



# Follow-up of access to cancer care

Definitions and guidelines

Valid from 1.1.2017

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**DIRECTIONS 4/2017**

**Follow-up of access to  
cancer care**

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**Valid from 1.1.2017**



**TERVEYDEN JA  
HYVINVOINNIN LAITOS**

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## To the reader

The project on following up and improving access to cancer care was launched and financed by the Ministry of Social Affairs and Health (STM) and carried out as a joint project with the National Institute for Health and Welfare (THL) and with the Cancer Society of Finland in 2015-2016. The objective of the project was to create a national follow-up and reporting system regarding access to cancer care.

THL was responsible for the project's coordination and practical implementation. Implementation work was carried out in cooperation with the Cancer Society of Finland.

The objectives of the project were:

- 1) to prepare a guide for following up on access to care;
- 2) to develop a system for collecting data regarding access to care; and
- 3) to develop a reporting system for national access to cancer care.

Another objective of the 'Follow-up of access to cancer care' guide was to harmonise the recording practices of cancer diagnoses and treatments. This would allow reliable monitoring of cancer patients' access to care, based on data recorded in the Hospital Discharge Register and reporting of access to care in Finland. The guide also specifies the appropriate time lines applicable in the follow-up of cancer care.

This guide is intended for those managing cancer patients' access to care, those in charge of recording access to care data, and those recording such data in the patient information systems. It is also useful for those who make changes to patient information systems and sampling, and other parties using data on cancer patients' access to care. Timely access to care is critical in the case of a number of cancers, in order to ensure a good clinical outcome. Efforts are also made to safeguard equal access to care for all citizens in situations where the patient is very concerned about the nature of the disease, even if the matter is not considered urgent in medical terms.

The project was followed and guided by a steering group, which comprised specialists from all university hospitals, Hyvinkää hospital, and Vaasa central hospital. The steering group also included specialists from the Ministry of Social Affairs and Health, the Cancer Society of Finland, Finnish Cancer Registry, and National Supervisory Authority for Welfare and Health (Valvira). Other participating members included medical specialists involved in the treatment of various cancers.

## Abstract

Maarit Sillanpää, Liisa Pyökkänen and Pirjo Häkkinen (ed.). Follow-up of access to cancer care. National Institute for Health and Welfare (THL). Directions 4/2017. 45 pages. Helsinki 2017. ISBN 978-952-302-820-3 (online publication)

The objective of the project was to create a national follow-up and reporting system on access to cancer care. The project involved the preparation of this guide, 'Follow-up of access to cancer care'. The definitions given in this guide served as a basis for the follow-up system for access to cancer care. This system enables national reporting on follow-up results.

Follow-up of access to cancer care will initially be conducted for 16 cancer types, which cover almost 75% of all new cancer cases reported each year (Finnish Cancer Registry<sup>1</sup>). In each cancer case, the follow-up covers the entire care path from the arrival of the referral to specialised medical care, the first appointment with a doctor (or telephone consultation or other similar arrangement) after the referral, placement on a waiting list, and the first cancer treatment. The dates are recorded to measure the time from the arrival of the referral to the first appointment with a doctor and the first treatment. Similarly, the time from placement on a waiting list to the first cancer treatment is measured.

The first cancer treatment can be surgery, chemotherapy, radiotherapy, other therapy (such as local cancer therapy), active surveillance, and palliative care. These different treatment options can be monitored using diagnostic and procedure codes. The various types of cancer treatments taken into account in cancer care follow-up and reporting, and their procedure codes, are listed in the guide.

In addition, the guide specifies the recommended maximum waiting times for the various care paths for breast, prostate and colorectal cancers, and the different stages involved starting from placement of a patient on a waiting list. These three cancers were selected due to their prevalence (Finnish Cancer Registry<sup>1</sup>). The recommended maximum waiting times are based on assessments by the steering group's medical specialists. They take account of the biological characteristics of each cancer type and the medical data available. In the future, the recommended maximum waiting times may be specified in more detail and their application may be extended to other common cancer types.

Key words: Diagnosis, cancer treatment, access to care, Hospital Discharge Register (Hilmo), procedure, follow-up, waiting time.

<sup>1</sup> <http://www.cancer.fi/syoparekisteri/>

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# 1 Background information on the development of cancer care in Finland

In 2010, a working group appointed by the Ministry of Social Affairs and Health (STM) in 2009, issued recommendations on the development of cancer care in Finland. Previous studies had shown that there was an unnecessarily long delay in access to cancer care (Working papers of the National Research and Development Centre for Welfare and Health, STAKES, 33/2008).

One of the action points included in the final report of the working group, ‘Development of cancer treatment in 2010–2020’ (STM Reports 6/2010), involves specifying maximum waiting times for cancer diagnosis and treatment. To continue the work carried out by the STM working group, the National Institute for Health and Welfare (THL) appointed an oncology specialist group for 2013–2014. This group published its report ‘Development of cancer prevention, early detection and rehabilitative support 2014–2025’ in May 2014 (THL Directions 6/2014). In addition, a report by a working group preparing the establishment of a National Comprehensive Cancer Centre was published in May 2014 (STM reports and memorandums 13/2014). Together, these reports provide a foundation for Finland’s cancer policy. The time requirements for access to cancer care were addressed in the first report only, which proposed the introduction of indicative maximum waiting times. The ultimate goal of enhanced follow-up of access to cancer care is to improve and accelerate early diagnoses and access to care, and thereby to contribute towards a more positive prognosis for cancers.

With regard to urgent care, current legislation only contains provisions on emergency care. The maximum waiting times for access to non-urgent care specified in the current legislation are too long for cancer patients. THL’s follow up data on access to specialised medical care currently cover the waiting times specified in the Health Care Act (sections 51–53 of the Health Care Act). In 2015, STM appointed a working group to revise and harmonise the waiting times and criteria for access to care, and the criteria for non-urgent and urgent care nationwide.

## 2 Data collection starting points

### 2.1 The project to follow up and improve access to cancer care

In late 2014, STM and THL launched a joint project to follow up and improve access to cancer care. For project implementation, THL partnered with the Cancer Society of Finland, whose representatives served as specialists in the project and participated in the coordination of cancer treatment expert resources required for the project. The project period was 15 November 2014 – 31 December 2015, but this was extended to 1 December 2016.

#### The project comprised the following areas:

- Preparation of a guide for the follow-up of access to cancer care
- Development of a system for collecting data on access to cancer care
- Development of a reporting system for national access to cancer care.

On 11 March 2015, the Director General of THL appointed a steering group for the follow-up and steering of the project. The chairperson of the steering group was Nea Malila, Director of the Finnish Cancer Registry, and its vice chairperson was Timo Keistinen, Ministerial Counsellor for Medical Affairs, Ministry of Social Affairs and Health. The steering group included medical specialists from all university hospitals, Hyvinkää Hospital and Vaasa Central Hospital (Table 1). Specialists from Valvira, the Cancer Society of Finland and THL were also included in the steering group.

**Table 1. Members of the steering group for the project to follow up and improve access to cancer care**

Member	Deputy member
Petri Bono, HUCH/HUS Chief Medical Officer	Mauri Kouri, HUCH Cancer Center/HUS Chief Medical Officer
Antti Jekunen, University of Turku, Vaasa Central Hospital, Oncology/TY/VSHP Chief Physician	Heidi Bengts, Vaasa Central Hospital, Oncology/VSHP Head of Department
Sirkku Jyrkkiö, TYKS, Operational Division of Surgery and Cancer Diseases/VSSHP Head of Division	Outi Lahdenperä, TYKS/VSSHP Medical specialist
Ulla Keränen, Hyvinkää Hospital, Department of Surgery /HUS Head of Division, Chief Medical Officer , Surgery (Member in 2015)	Juhani Sand, TAYS/PSHP Head of Division, Chief Medical Officer
Katariina Klintrup, OYS/PPSHP Department of Oncology and Hematology Deputy Chief Medical Officer, Head of Department	Merja Korpela, OYS/PPSHP Department of Oncology and Hematology , Specialist in Oncology and Radiotherapy
Tuula Lehtinen, TAYS/PSHP Chief Medical Officer, Head of the Department of Oncology	Maarit Bärlund, TAYS/PSHP Assistant Chief Medical Officer
Anna Lepistö, HYKS/HUS Head of Colorectal Surgery Department (Member in 2016)	
Kristiina Tyynelä-Korhonen, KYS/PSSHP Chief Medical Officer, The Chief of the Center of Oncology, Obstetrics and Gynecology	Päivi Auvinen, KYS Chief Physician
Aino Lepäntalo, HYKS/HUS Medical specialist	



Kirsi Liukkonen, Valvira Senior Officer, Legal Affairs	Leena-Maija Vitie, Valvira Senior Officer, Legal Affairs
Liisa Pylkkänen, the Cancer Society of Finland Chief Medical Officer	
Pirjo Häkkinen, THL Development Manager	
Aleksi Yrttiaho, THL Development Manager	Jaason Haapakoski, THL Senior Specialist
Maarit Sillanpää, THL Project Manager	

Other specialists invited to participate in the preparation of this guide included Juho Lehto, Chief Physician (Palliative Care Unit, Department of Oncology, TAYS and the University of Tampere), and the Medical Specialists listed below, who were consulted on the surgical treatment of different cancers.

**Table 2. Specialists in the treatment of different cancers**

Medical Specialist	Cancer
Peter Boström, TYKS/VSSH Chief Medical Officer, Urology	Bladder and urinary tract cancer
Sakari Hietanen, TYKS/VSSH Head of the Division	Endometrial and ovarian cancer
Sirkku Jyrkkö, TYKS, Operational Division of Surgery and Cancer Diseases/VSSH Head of division	Lymphomas
Petri Koivunen, OYS/PPSH Chief Medical Officer	Head and neck cancers
Aki Laakso, HYKS/HUS Administrative Deputy Chief Physician	Brain and central nervous system cancers
Marjut Leidenius, HYKS/HUS Head of Department	Breast cancer
Anna Lepistö, HYKS/HUS Head of Colorectal Surgery Department	Colon and rectal cancer
Mika Matikainen, HYKS/HUS Chief Medical Officer	Prostate and testicular cancer
Harry Nisén, HYKS/HUS Senior Physician	Kidney cancer
Juhani Sand, TAYS/PPSH Head of Division, Chief Medical Officer	Pancreatic and stomach cancer
Eero Sihvo, Central Finland Central Hospital/KSSH Chief Medical Officer	Lung and tracheal cancer
Meri-Sisko Vuoristo, Pirkanmaa Cancer Society Chief Medical Officer	Melanoma

Abbreviations used for the hospitals: HUCH Helsinki University Central Hospital, KYS Kuopio University Hospital, OYS Oulu University Hospital, TAYS Tampere University Hospital and TYKS Turku University Central Hospital. TY University of Turku.

Abbreviations used for the hospital districts: HUS Hospital district of Helsinki and Uusimaa; KSSH Hospital district of Central Finland, PPSH Hospital district of North Ostrobothnia, PSHP Hospital district of Pirkanmaa, PSSHP Hospital district of North Savo, VSHP Hospital district of Vaasa, and VSSH Hospital district of Southwest Finland.

THL's Senior IT System analysts Raimo Mahkonen and Satu Kerppilä also participated in the development of the follow-up and reporting of access to cancer care.

## 2.2 Legislation

The Act on the Statistical Service of the National Research and Development Centre for Welfare and Health (409/2001) provides the legal basis for the collection of data on access to cancer care. The collection of data on inpatient and outpatient health care (Hilmo data collection) is based on the Act (556/1989) and Decree (774/1989) on National Personal Records Kept under the Health Care System. Pursuant to Section 11 of the Act on the National Institute for Health and Welfare (668/2008), these acts have been applied to THL's activities since 1 January 2009. In addition, amendments to legislation being circulated for statements with regard to the legislative proposals 'Secure use of social welfare and health care data and certain related acts' and 'The organisation of social welfare and health care and certain related acts' will, once they enter into force, affect the legal basis of data collection.

## 2.3 Purpose of use

The purposes for which the data on cancer diagnosis and access to care will be used:

- To provide information on the follow-up, supervision and statistics regarding access to cancer care
- To provide information for research and decision-making
- To serve as a health care system performance indicator.

# 3 Principles applied in the collection of data

This guide specifies the necessary time points, time intervals, concepts and procedures relevant to the follow-up of cancer patients' access to care. It also provides instructions for the recording of various cancer treatment procedures and diagnoses.

The instructions for the collection of data on access to cancer care are intended for the following:

- Those in charge of implementing access to cancer care
- Those in charge of supervision of access to cancer care
- Those in charge of consistent recording of data regarding access to care and of providing instructions to users
- Those entering access to care data in the patient information systems
- Those making changes in patient information systems and sampling
- Those utilising cancer patients' access to care data.

THL is responsible for the maintenance and development of data content, classification, sampling and reporting related to access to cancer care. Similarly, working groups involved in access to specialised medical care can contribute their expertise to the specification and development work of cancer care. These working groups consist of representatives of the hospital districts, primary health care, specialised medical care, patient information system suppliers, THL, STM, Regional State Administrative Agencies and Valvira. In addition, the insights and policies of THL's Hilmo expert group affect development and maintenance work related to the follow-up of cancer care, because the cancer care information is included in Hilmo data. An expert group or network will be appointed to oversee the improvement of access to cancer care and quality assurance.

## 3.1 Data collection is based on data in the Hospital Discharge Register

The Hospital Discharge Register (Hilmo) provides the foundation for the follow-up of access to cancer care.

According to law, municipalities and joint municipal authorities, members of the public and some private health care service providers (inpatient care and day surgery), and health care and pharmacy personnel have an obligation to provide information to THL free of charge, confidentiality provisions notwithstanding. According to law, health care information will be recorded for each patient, alongside identifying personal information. Only information relevant to the health care units' operations and allocation of activities will be recorded.

THL's Hilmo register provides information on different types of care episodes such as in-patient care, day surgery visits, outpatient visits and procedures performed during such visits. Information on radiotherapy and chemotherapy can also be obtained from Hilmo data, when the procedure codes are accurately recorded in the patient information systems. Hilmo data also contains the cancer diagnoses required for the follow-up of access to cancer care, recorded according to the ICD-10 disease classification. In the future, these codes and diagnostic information can offer valuable information on the treatment of metastatic/recurrent cancer. Dates regarding referrals and placement on a waiting list can also be obtained from Hilmo.

Key epidemiological data, such as data on new cancer cases and patient mortality, are obtained from the Finnish Cancer Registry<sup>2</sup>. Information regarding care systems and cancer prevention is available from THL, and from data and studies compiled by the Finnish Institute of Occupational Health (TTL)<sup>3</sup> and the Radiation and Nuclear Safety Authority (STUK)<sup>4</sup>.

2 <http://www.cancer.fi/syoparekisteri/>

3 <https://www.ttl.fi/en/>

4 <http://www.stuk.fi/>

# 4 Follow-up of access to cancer care

## 4.1 Development needs regarding follow-up of access to cancer care in Finland

According to the recommendations of a working group appointed by the Ministry of Social Affairs and Health for the development of cancer treatment, demanding surgery, diagnosis and treatment requiring special expertise or expensive investments should be organised centrally. Some cancer treatments can be planned centrally but provided locally, closer to the patient's residence. According to expert evaluations, primary health care will be increasingly involved in the follow-up and palliative care of cancer patients (STM Reports 6/2010).

With this background information in mind, the working group made suggestions for the improvement of cancer care, in order to clearly define roles and responsibilities, and to set maximum waiting times for access to cancer care. The maximum waiting time for patients with suspected cancer, from referral to first treatment (surgery, chemotherapy or radiotherapy), is 6 weeks. For patients with cancers requiring urgent treatment, the waiting time must be shorter. Treatment should begin within a few days or within 2-3 weeks from the diagnosis at the latest. If cancer is suspected, the radiology report of the imaging test must be available within one week from the referral for such a test. If cancer is suspected, a tissue sample (surgical or needle biopsy) must be taken within one week from the arrival of a request for examination at the surgical unit or imaging unit. A pathologist's report must be available within one week from the tissue biopsy, unless a cancer diagnosis requires the use of special diagnostic tests. Any adjuvant therapies after surgery (radiotherapy or chemotherapy) must commence no later than 4 weeks after surgery, unless a longer period is required for patient-related reasons (such as recovery from the surgical procedure).

The working group for the development of cancer treatment proposed that the maximum waiting times specified above should, as a rule, also apply to the diagnostics and treatment of recurrent cancer. Treatment for difficult or severe cancer-related symptoms such as pain, impending paresis, or venous or other blockages, should be available without delay in all care units.

## 4.2 Follow-up of access to cancer care in some other countries

In other Nordic countries, there are varying practices for following up patients' access to cancer care. In Denmark, recommendations have been issued for cancer-type specific times for different treatments (surgery/chemotherapy/radiotherapy). The time from referral to first treatment is monitored as a rule. Adherence to these recommended times is monitored in five regions in Denmark and for the entire country, quarterly and yearly. Furthermore, an annual analysis is prepared to indicate the percentage of patients that received treatment within the recommended time<sup>5</sup>. In Denmark, the cancer treatment follow-up system covers 33 different types of cancers, including pediatric cancers as one entity.

The follow-up model used in Norway is very similar to the one used in Denmark. There are recommended times for different cancer types, and they are very short<sup>6</sup>.

<sup>5</sup> <http://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/monitoreringer/kraeft>

<sup>6</sup> <https://helsedirektoratet.no/kreft>

In Sweden, the time monitored covers the period from the preparation of a referral to the first treatment for bladder, kidney, colon, prostate and rectal cancers. For cancers of the head and neck and for lung cancers, the time span monitored is from referral to first treatment, for breast cancer from the first specialist appointment to treatment, and for melanoma from first specialist appointment to diagnosis. The medians of these time lines are monitored and reported annually for the different regions of Sweden, and for the entire country<sup>7</sup>.

In England, the cancer treatment follow-up model is based on time recommendations, which apply to the treatment of all cancers. The general recommendations provide the following time lines: No more than two weeks from a GP's urgent referral to first consultant appointment for a case of suspected cancer, and no more than 2 months from a GP's urgent referral to treatment. In addition, the maximum time from a decision to treat to the first treatment is one month, from a referral by a national screening service to first treatment 62 days, and to second or subsequent treatment 31 days. This data is reported monthly and annually<sup>8</sup>.

### 4.3 Principles for the follow-up of access to cancer care

The objective of conducting the follow-up of patients' access to cancer care is to provide regional and provider-specific information on how long patients must wait before they receive treatment for their cancer. Follow-up focuses on the time from a specific cancer diagnosis to access to the first cancer treatment; this treatment may be surgery, chemotherapy, radiotherapy, other cancer treatment, active surveillance, or palliative treatment (Figure 1). Treatment may be given for primary or recurrent/metastatic cancer. Surgical operations to be followed up for each type of cancer are listed in the section 4.5.2 'Recording cancer operations'. The treatment procedures to be followed up include surgical treatment, chemotherapy and radiotherapy given at all stages of the cancer (primary/recurrent/metastatic). The key objective is to follow up on the first treatment.

#### 4.3.1 The essential definitions and follow-up times

##### Definitions

**A referral** is a document in which a social welfare and health care service provider submits a service request concerning a customer to another service provider.

**Received referral** means the first referral for the health problem in question (Hilmo guidance).

- Urgent referrals for the same health problem will not create a new event.
- Inter-organisational transfers between wards, specialties or departments do not require a new referral if the patient is being treated for the same health problem.
- An internal referral is required if a new health problem is being treated and responsibility for care transfers to another specialty and department. An internal referral transfers responsibility for care to another specialty or department within the same organisation.
- For patients requiring emergency care or patients with no referral, the patient's arrival date is recorded as the referral arrival date.

<sup>7</sup> <http://www.socialstyrelsen.se/sjukdomar/cancer>

<sup>8</sup> <http://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>

**Referral arrival date** is the date on which the referral was first received by an institution or specialised medical care unit for the assessment of a health problem (Hilmo guidance).

**First appointment with a doctor** at the care unit in question is the patient's first contact with the doctor after the arrival of the referral with regard to the disease/health problem in question.

- This first contact may be a personal visit to a doctor, or a telephone consultation or similar, if it replaces the first visit and is a personal consultation for which an appointment was made beforehand.

**Date of placement on waiting list** is the date on which a patient is placed on a waiting list to wait for inpatient care, day surgery or outpatient treatment, operation or procedure. Patients should be placed on a waiting list on the same day as the doctor makes a decision to start treatment (Hilmo guidance).

**Adjuvant therapy** refers to treatment given soon after the local treatment of the tumour (usually an operation, sometimes radiotherapy). Adjuvant therapy is provided to destroy any cancer cells that cannot be eliminated using surgery or radiotherapy. The patient may be given only one adjuvant therapy, or several therapies either in succession or simultaneously.

- Neoadjuvant therapy for cancer is provided before the operation or radiotherapy.

**Active surveillance of a diagnosed cancer** is recorded if the doctor estimates that treatment to cure cancer with surgery, radiotherapy or chemotherapy is not necessary but, instead, the patient's condition can be regularly monitored. Treatment for cancer will be started if the cancer progresses or becomes more poorly differentiated.

- Active surveillance of a diagnosed cancer may be a suitable approach for well differentiated, local (low risk of progression) prostate cancer, small and well differentiated kidney cancers, and low-grade malignant lymphoma with slow progression. This will help to avoid the unnecessary side effects of cancer treatment.
- Active surveillance of a diagnosed cancer is recorded when a patient's cancer is not initially treated, only monitored for potential progression. This is not recorded at other stages of the chain of care.
- Procedure code XZZ00 is used for the active surveillance of a diagnosed cancer. This procedure code will be included in the THL Classification of Procedures in Medicine<sup>9</sup> as of the beginning of 2017.

For example, the following would be recorded for the active monitoring of a patient with prostate cancer:

- Diagnosis: prostate cancer C61
- Procedure: Active surveillance of a diagnosed cancer XZZ00

<sup>9</sup> [www.thl.fi/codeservice](http://www.thl.fi/codeservice)

**Palliative, or symptomatic cancer care** refers to the active comprehensive treatment of a cancer patient with the objective of alleviating the physical, psychological, social and mental suffering caused by the disease. As the disease advances, the need for palliative care usually increases. When treatment to slow down the progression of the disease is no longer effective or not in the patient's best interests due to severe side effects, palliative care will be provided. Instead of attempting to slow down the progression of cancer, the focus is on alleviating the symptoms and maintaining the patient's quality of life.

- The doctor will record palliative care Z51.5 as the secondary diagnosis, and planning of intervention or health care consultation WZC00 as the procedure code.

For example, the following would be recorded for a lung cancer patient's palliative care:

- Primary diagnosis: lung cancer, e.g. C34.32 (Malignant neoplasm of lower lobe, left bronchus or lung; adenocarcinoma)
- Secondary diagnosis: palliative cancer care Z51.5
- Planning of intervention or health care consultation WZC00 during an appointment

### Waiting times to be followed up

The dates to be observed with regard to access to cancer care and treatment are the arrival of the referral, the first appointment with a doctor, placement on a waiting list, and the first cancer treatment (Figure 1).

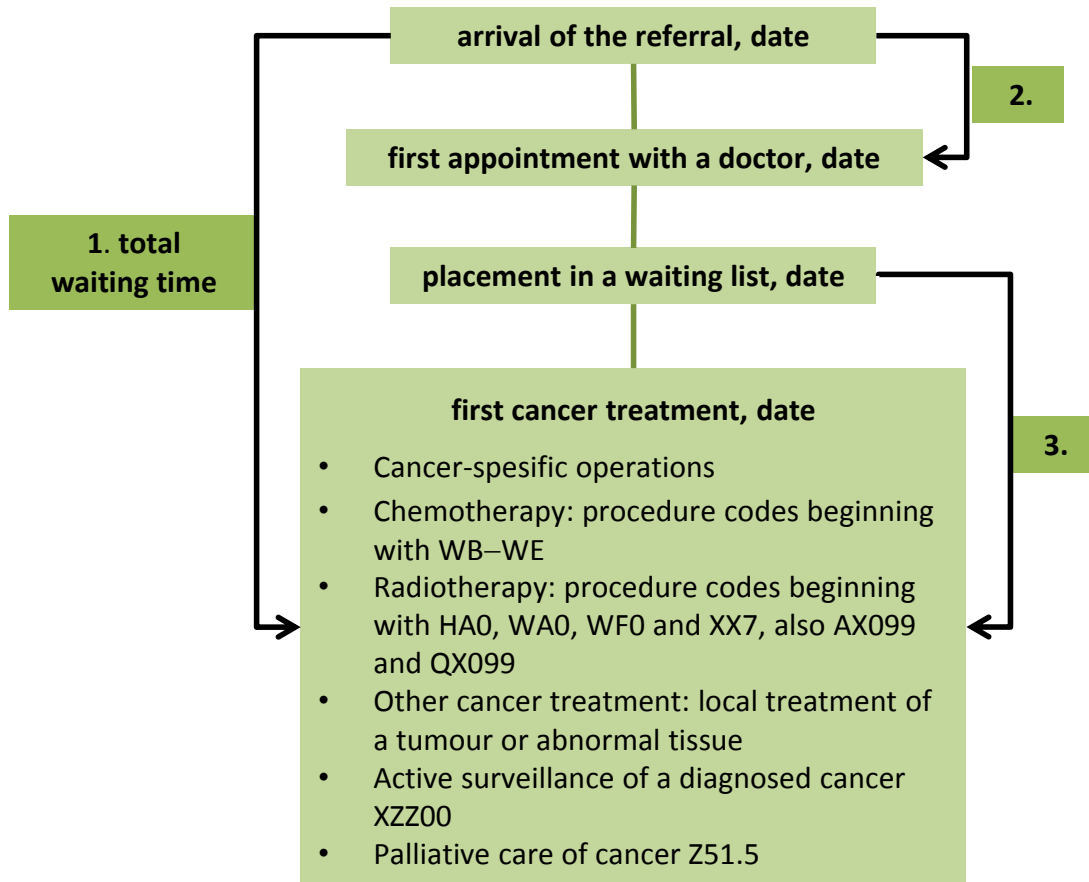
**First cancer treatment** is the treatment provided soonest after the arrival of the referral or placement on a waiting list. A cancer patient's treatment options include surgery, chemotherapy, radiotherapy, or other treatment (various local treatments). Other alternatives include active surveillance of the cancer and symptomatic, or palliative care. These procedures used for the treatment of different types of cancers are determined on the basis of the THL Classification of Procedures in Medicine and THL Classification of Diseases ICD-10<sup>10</sup>:

- Cancer-specific operations (tables 4–7)
- Chemotherapy: procedure codes beginning with WB–WE (tables 8–10)
- Radiotherapy: procedure codes beginning with HA0, WA0, WF0, XX7, AX099 and QX099 (table 11)
- Other cancer treatment: Local treatment of a tumour or abnormal tissue (table 12)
- Active surveillance of a diagnosed cancer: XZZ00 procedure code will be included in the THL classification of Procedures in Medicine as of the beginning of 2017).
- Palliative care of cancer: Z51.5.

<sup>10</sup> [www.thl.fi/codeservice](http://www.thl.fi/codeservice)



Figure 1. The time points and time intervals relevant to the follow-up of cancer patients' access to care



Time intervals are measured on the basis of the following time points: arrival of the referral, first appointment with a doctor, placement on a waiting list, and the first cancer treatment.

### 1 Arrival of the referral – First cancer treatment

This is the waiting time in full days from the arrival of the referral to the first cancer treatment.

### 2 Arrival of the referral – First appointment with a doctor

This is the waiting time in full days from the arrival of the referral to the first appointment with a doctor.

### 3 Placement on a waiting list – First cancer treatment

This is the waiting time in full days from the placement on a waiting list to first treatment.

The cancer treatment procedures may be recorded under primary or secondary procedures (THL – Classification of Procedures in Medicine <sup>11</sup>).

11 [www.thl.fi/codeservice](http://www.thl.fi/codeservice)

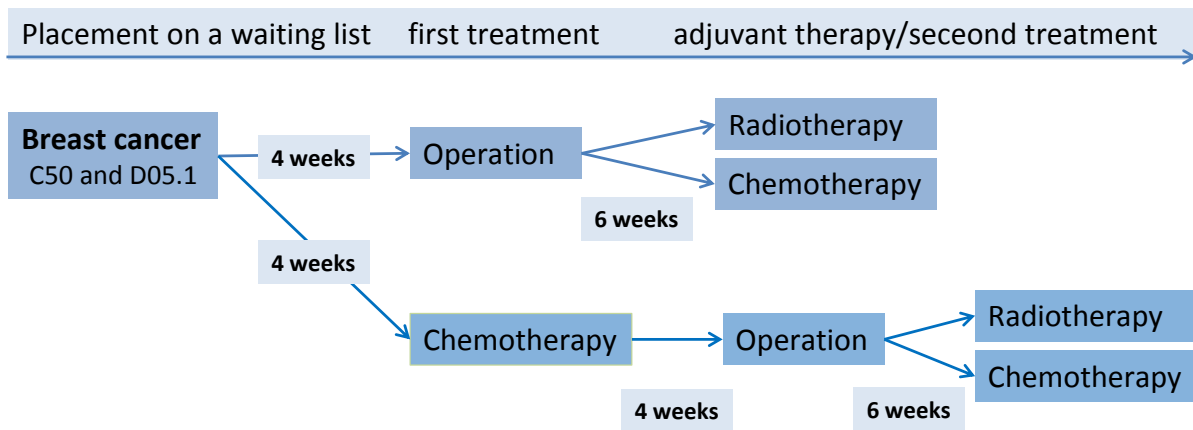
### 4.3.2 Follow-up of breast cancer, prostate cancer and colorectal cancers

The recommended maximum waiting times for access to cancer care for the following cancers

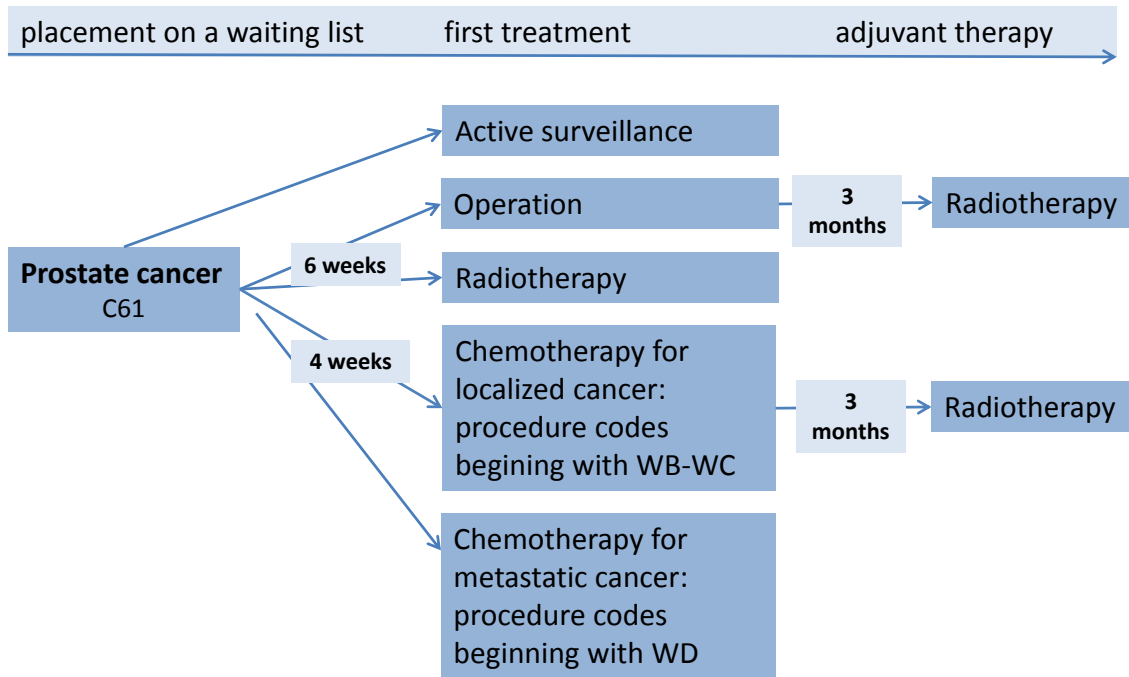
- Invasive breast cancer and intraductal breast cancer (diagnoses beginning with C50 and D05.1) (Figure 2)
- Prostate cancer (diagnoses beginning with C61) (Figure 3)
- Colon and rectal cancer (diagnoses beginning with C18-20) (Figures 4 and 5)

The recommended maximum waiting times for alternative care pathways are presented from the date of placement on a waiting list. The recommended maximum waiting times are based on assessments by the steering group's medical specialists. They take account of the biological characteristics of each cancer type and the medical data available.

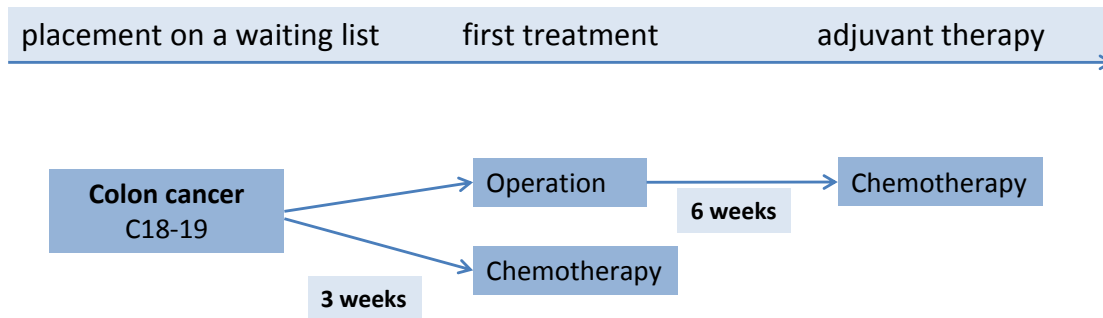
**Figure 2. The recommended maximum waiting times for breast cancer patients from placement on a waiting list to first treatment and postoperative adjuvant therapies**

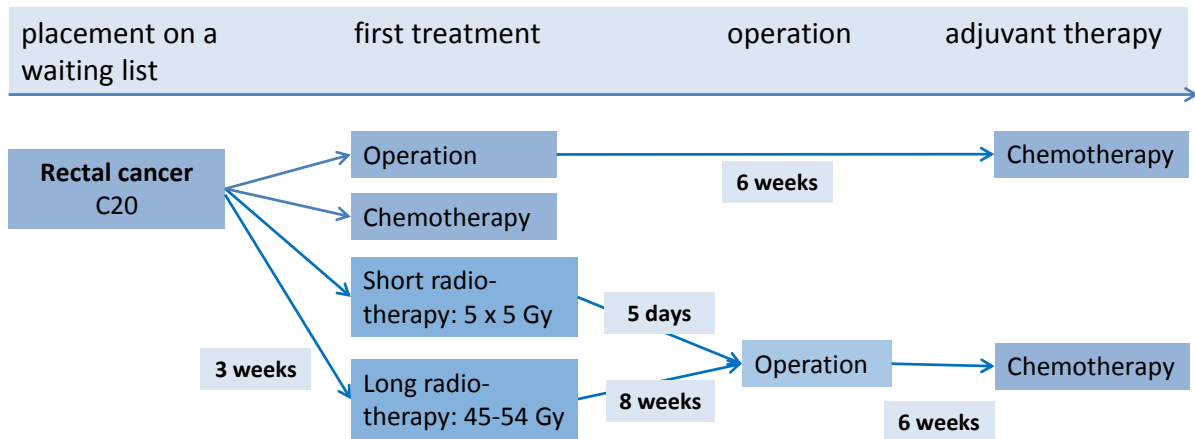


**Figure 3. The recommended maximum waiting times for prostate cancer patients from placement on a waiting list to first treatment and adjuvant radiotherapy**



**Figure 4. The recommended maximum waiting times for colon cancer patients**



**Figure 5. The recommended maximum waiting times for rectal cancer patients**

#### 4.3.3 Other common cancers and their follow-up

With regard to other cancers, the most common cancers and patients' access to care are followed up until the first treatment, and reported using indicators as a median time to treatment. Table 3 contains a list of other cancers being followed up, with their THL Classification of Diseases ICD-10 compliant codes. Some less common cancers were also included which require urgent care (e.g. testicular cancer). In the future, follow up may be extended also to other cancers.

**Table 3. Other cancers included in the follow-up of access to care and their ICD-10 codes**

Cancer	ICD-10 codes
Head and neck cancers	C00-14 and C30-32
Stomach cancer	C16
Pancreatic cancer	C25
Lung and tracheal cancer	C33-34
Melanoma	C43
Endometrial cancer	C54
Ovarian cancer	C56, C57.0-8
Testicular cancer	C62
Kidney cancer	C64
Bladder and urinary tract cancer	C65-68
Brain and central nervous system cancers	C70-72+C75.1-3
Lymphomas	C81-85

## 4.4 Relevant data in the follow-up of access to cancer care

### 4.4.1 Surgery

Relevant data on cancer operations includes the patient's first actual cancer operation to remove local, recurrent or metastatic cancer. These operations do not include exploratory surgery, surgical opening of an area or a biopsy, which are included in cancer diagnostics. Similarly, corrective procedures or operations performed to deal with complications are not included in the follow-up of access to cancer care, with the exception of exploratory surgery conducted with the intention to treat metastatic cancer (such as pancreatic cancer) but which remains an exploratory surgery. Similarly, palliative surgical procedures (such as surgical treatment of a bowel obstruction caused by intestine cancer) are considered procedures to be followed up (tables 4–7).

### 4.4.2 Chemotherapy

The procedure codes beginning with WB, WC, WD and WE in the THL Classification of Procedures in Medicine signify chemotherapy. Codes beginning with WB cover various drug therapies for a local primary tumour: cytotoxic drugs, immunomodulators, hormone therapies, antibody therapies, enzyme inhibitor therapies and other drug therapies to fight cancer. The procedure code also includes a description of the level of treatment: simple, demanding or very demanding. The procedure codes also help to describe whether the treatment was given as an adjuvant therapy, or before or after surgery or radiotherapy (neoadjuvant therapy).

The procedure codes beginning with WC refer to drug therapies for locally recurrent tumours or individual metastasis. They usually cover the same treatment options as those listed for primary tumours. The procedure codes beginning with WD refer to drug therapies for metastatic cancer. The procedure codes beginning with WE refer to preventive cancer treatment.

### 4.4.3 Radiotherapy

The procedure codes for radiotherapy beginning with WF0 refer to local radiotherapy. They also describe the stage of the patient's treatment during which the therapy is given, and whether treatment is given for a primary tumour or metastatic cancer. The procedure codes beginning with WA refer to radiation therapy given on large areas of skin or body. There are also procedure codes beginning with HA0, which refer to radiation therapy given to the chest area, and procedure code AX099 for the central nervous system and QX099 for the skin. The procedure codes for radioisotope therapies begin with XX7.

### 4.4.4 Other treatments

Other types of cancer treatment subject to follow-up include stem cell transplantation procedure codes beginning with WW\_) and local treatments of tumours or abnormal tissue.

## 4.5 Instructions for recording cancer treatment

The THL Classification of diseases ICD-10<sup>12</sup> is used for recording the diagnoses of cancer patients, while the THL Classification of Procedures in Medicine<sup>13</sup> is used for recording operations performed and chemotherapies, radiotherapies and other treatments given during inpatient stays and visits.

### 4.5.1 Instructions for recording diagnoses

The objective of the guide for structured recording in the health care sector (How to record the main record structures in electronic patient records, Part I, Version 2015) is to describe the recording practices and use of nationwide harmonised and structured patient data from the perspective of the person recording or using the data. The guide has been updated to match the situation in 2017–2018. The guide for structured recording practices provides general instructions on how to record the reason for visit, reason for treatment and diagnoses.

Instructions for recording diagnoses are also provided in a Finnish guide for recording diseases (THL Guide 17/2012) and in the THL Classification of Diseases ICD-10. The instructions of the Hilmo guide (THL Directions 11/2016) on recording diagnoses are also consistent with those provided in the guide for structured recording practices and the Finnish guide for recording diseases referred to above.

#### **Principal diagnosis or reason for care period or visit**

The guide for structured recording provides the following instructions: *‘Primary and secondary diagnoses are attributes used in the patient record to describe the significance of the recorded diagnosis in connection with each visit or inpatient stay. Primary diagnosis refers to the diagnosis that is the main reason for the patient’s treatment in the given care situation. Secondary diagnoses refer to other diagnoses that are of lesser importance but which nevertheless affect the examination, treatment, prognosis or health of the patient.’*

*Information indicating the principal nature of the diagnosis or reason for visit is recorded in accordance with the Principal diagnosis classes as primary and secondary. A primary diagnosis must be specified by the end of the inpatient stay or appointment at the latest. The health problem or disease that was the main reason for the visit or inpatient stay in question is recorded as the primary diagnosis. Only one primary diagnosis can be recorded for each appointment or inpatient stay.’*

#### **Recording diagnoses in cancer care**

When a patient is treated for cancer and the cancer has metastasised, both the primary and metastatic cancer are recorded, with their specific THL Classification of Diseases ICD-10 codes.

The cancer diagnoses refer only to primary cancers and do not provide any information on metastasis. The THL Classification of Diseases ICD-10 contains separate diagnostic codes for metastasis (C77-79). These indicate the location of the metastasis but not its origin.

#### **How to record long-term cancer diagnoses**

Cancer diagnoses are recorded as long-term diagnoses. Existing conditions such as prostate cancer should be accounted for with respect to the patient’s potential other diseases.

Similarly, palliative treatment of cancer (Z51.5) is also recorded as a long-term diagnosis.

<sup>12</sup> [www.thl.fi/codeservice](http://www.thl.fi/codeservice)

<sup>13</sup> [www.thl.fi/codeservice](http://www.thl.fi/codeservice)

**Permanence of the diagnosis or reason for visit**

The guide for structured recording provides the following instructions: *‘Permanence refers to the time dimension of the diagnosis in the patient’s care. Permanence has to do with whether or not the diagnosis results in a long-term need for treatment, or whether it will affect the treatment provided for future health problems or other diseases. If relevant in terms of treatment, long-term diagnoses will also be recorded as diagnoses for the visit or inpatient stay.*

*The permanence of the diagnosis can, where necessary, be described using the Permanence classes. A diagnosis can be made for a fixed term or on a permanent basis.*

*A permanent diagnosis is made for the longer term and may have special relevance to the patient’s health, well-being and treatment, even after the disease or health problem has cleared up. Long-term diagnoses are often relevant to most contacts with patients, even if they were not the direct reason for seeking treatment, and are therefore often recorded as secondary diagnoses for visits and inpatient stays. Long-term diagnoses are listed in a summary of diagnoses provided by the Information Management Service, and remain listed until recorded as having ended.’*

**4.5.2 Instructions for recording cancer operations**

As noted above in section 4.4.1, relevant data on cancer operations includes the patient’s first actual cancer operation to remove local, recurrent and metastatic cancer. The purpose is to report the first treatment given, which in the case of advanced cancer can also mean palliative or exploratory surgery.

Lymph node removal operations are considered primary cancer treatment subject to a follow-up, except in the case of lymphomas. In lymphoma patients, lymph node removals are considered diagnostic procedures and are not therefore included as operations to be followed up (table 7).

With regard to cancers subject to follow-up for access to care, operations are grouped as follows: breast cancer operations in table 4, prostate cancer operations in table 5, colorectal cancer operations in table 6, and other cancer operations (cancer of the head and neck area, stomach, pancreas, lungs and trachea; melanoma, corpus uteri, ovaries, testicles, kidneys, bladder and urinary tract, brain and central nervous system, and lymphomas) in table 7.

**Surgical treatment of breast cancer**

Surgical treatment of breast cancer is planned in consultation with the patient, taking account of the size of the tumour, the size of the patient’s breasts, and any pre-existing conditions the patient may have. A breast-conserving operation should always be performed upon the patient’s request, unless there are contraindications. If a total mastectomy is required, the removed breast can be reconstructed either after the cancer operations, or after the adjuvant therapies have been completed. Reconstructive surgery is a major operation that often involves complications. That is why the patient must be in relatively good physical condition, motivated and well-informed.

If an axillary metastasis has been diagnosed before the operation, an axillary lymph node evacuation will be performed. If no axillary metastasis has been diagnosed, a sentinel lymph node biopsy is generally performed. The findings of this biopsy determine whether axillary lymph node evacuation, radiotherapy, or both are required, or whether monitoring will suffice.

If the breast cancer (either the primary tumour or the lymph node metastases) has spread locally, the first treatment given is drug therapy (neoadjuvant therapy). The operation performed following this therapy usually involves removing the breast and the axillary lymph nodes.

The Finnish Breast Cancer Group has issued recommendations concerning breast cancer diagnosis and treatment, which are available on the organisation's website<sup>14</sup>.

Procedures beginning with HAD (corrective procedures) are not subject to surgical breast cancer treatment follow-up, with the exception of early-stage HAD30, which may be used as a surgery code in some hospitals, if breast reduction surgical technique is used to perform the cancer operation. In the future, these types of operations will be recorded with the procedure code HAB50.

**Table 4. Surgical procedures subject to breast cancer treatment follow-up**

ICD-10 codes for breast cancer beginning with C50 and D05.1			
	Name of the group	Code	Procedure
<b>HAB</b>	Partial excision of mammary gland	HAB30	Excision of mamilla or areola
		HAB40	Wedge excision of mammary gland
		HAB50	Partial excision of mammary gland with reconstructive operation Includes: Oncoplastic resection
		HAB99	Other partial excision of mammary gland
<b>HAC</b>	Mastectomy	HAC10	Subcutaneous mastectomy with preservation of mamilla
		HAC15	Subcutaneous mastectomy with excision of mamilla
		HAC20	Total mastectomy
		HAC25	Radical mastectomy
		HAC30	Excision of supernumerary mammary gland or mamilla
		HAC99	Other mastectomy
		<b>HAD</b>	Plastic operations on breast
<b>HAF</b>	Operations for local recurrence of breast cancer	HAF00	Excision of local recurrence of breast cancer
		HAF10	Repair after excision of local recurrence of breast cancer using graft or flap
<b>PJA</b>	Exploration of lymph nodes	PJA12	Sentinel node biopsy
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD42	Excision of axillary lymph nodes
		PJD52	Block dissection of axillary lymph nodes

\* This code may be used in some hospitals if breast reduction surgical technique is used to perform the cancer operation.

<sup>14</sup> <http://rintasyoparyhma.yhdistysavain.fi/hoitosuositus/>



## Surgical treatment of prostate cancer

Treatments aimed at curing local (T2) or locally advanced (T3N0M0) prostate cancer include radical surgery or radiotherapy. The most common surgical procedure for curing prostate cancer is a radical prostatectomy, which means removal of the prostate and the prostatic capsule. There are different types of radical prostatectomy: open (KEC00), minimally invasive laparoscopic (KEC01), or robot-assisted laparoscopic (KEC01, ZXC96) prostatectomy, the last-mentioned currently being the most common type of radical surgery. The techniques used to perform open radical prostatectomy are retropubic (KEC00), perineal (KEC10) and transcoccygeal (KEC20) prostatectomy, the first one being clearly the most common.

In local prostate cancer, the goal of radical prostatectomy is to remove the prostate and the prostatic capsule, to remove all cancer tissue and thereby to cure the patient, and to minimise the harmful side effects of the operation in terms of postoperative morbidity, incontinence and sexual dysfunction. A radical prostatectomy usually involves removing the seminal vesicles attached to the prostate. In the case of medium or high-risk patients, the procedure includes extended lymph node dissection around the iliac arteries (PJD64). For low-risk patients, because the probability of lymph node metastasis is small, no lymph node removal is generally required.

In certain, special cases, second-line salvage treatment may include a radical prostatectomy, if the cancer recurs locally after radical radiotherapy. However, the risks of complications are significantly higher than in an operation performed as first-line treatment.

The first-line treatment for metastatic prostate cancer is hormone therapy, which may involve a chemical castration with LHRH analogues or antagonists, or surgical castration which involves removing both testicles (KFC10). Orchiectomy, or removal of the testicles, may involve total removal by cutting the funicles, or a subcapsular orchiectomy which involves saving the tunica albuginea and only removing the intracapsular testicular tissue.

The recommendations for the diagnostics and treatment of prostate cancer prepared and updated by the Current Care Guidelines working group on prostate cancer are available on the Current Care Guidelines website <sup>15</sup>.

**Table 5. Surgical procedures subject to prostate cancer treatment follow-up**

ICD-10 codes for prostate cancer beginning with C61			
	Name of the group	Code	Procedure
<b>KEC</b>	Total excision of prostate and seminal vesicles	KEC00	Retropubic radical prostatectomy
		KEC01	Percutaneous endoscopic radical prostatectomy
		KEC10	Perineal radical prostatectomy
		KEC20	Transsacral radical prostatectomy
		KEC30	Removal of seminal vesicle
<b>KFC</b>	Total excision of testis and epididymis	KFC10	Bilateral orchiectomy
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD44	Excision of iliac lymph nodes
		PJD54	Block dissection of iliac lymph nodes
		PJD64	Laparoscopic dissection of iliac lymph nodes

<sup>15</sup> <http://www.kaypahoito.fi/web/english/home>

## Surgical treatment of colorectal cancers

The most common, first surgical treatment of colorectal cancer is the removal of the tumour. In colon cancer, surgery most typically involves a right and left hemicolectomy, depending on the location of the cancer. Sometimes a total colectomy may be required, after which the small intestine is connected to the rectum. This procedure may be necessary if the patient has multiple tumours in the colon, or is genetically predisposed to colon tumours.

The most common surgical treatments for rectal cancer are an anterior resection and abdominoperineal excision. An anterior resection involves removing the rectum and the lymph nodes in this part of the bowel, and joining the remaining parts of the colon and the rectum. In this type of operation, a temporary stoma may be required to protect the anastomosis. If the rectal cancer is located very low in the rectum, the anus will have to be removed. An abdominoperineal excision involves removing the rectum, the sphincter muscles around the anus and, in locally advanced T3-T4 tumours, the pelvic diaphragm. The patient will have a permanent colostomy. When rectal cancer is associated with polyposis, a proctocolectomy is typically performed to remove the entire colon and rectum. Sometimes the procedure may involve the construction of an ileal reservoir which is connected to the anus (ileoanal anastomosis), or, alternatively, a permanent ileostomy.

If the patient needs preoperative radiotherapy for the rectal cancer but the tumour is blocking the bowel, a loop transverse colostomy is performed before radiotherapy to ensure that the patient can eat and have bowel movements during radiotherapy. A stoma also helps to alleviate the patient's symptoms in a situation where the disease has advanced locally to the point that surgical removal of the tumour is no longer an option.

**Table 6. Surgical procedures subject to colorectal cancer treatment follow-up**

ICD-10 codes for colorectal cancers beginning with C18-20			
	Name of the group	Code	Procedure
<b>JAH</b>	Opening of peritoneal cavity	JAH00	Laparotomy
<b>JFA</b>	Local operations on intestine	JFA68	Endoscopic insertion of prosthetic tube into colon
		JFA83	Excision of lesion of colon
		JFA84	Laparoscopic excision of lesion of colon
		JFA96	Other local operation on intestine
		JFA97	Other laparoscopic local operation on intestine
		JFA98	Other transluminal endoscopic local operation on intestine
<b>JFB</b>	Partial excision of intestine	JFB20	Ileocaecal resection
		JFB21	Laparoscopic ileocaecal resection
		JFB30	Right hemicolectomy
		JFB31	Laparoscopic right hemicolectomy
		JFB33	Other resection comprising small intestine and colon
		JFB40	Resection of transverse colon
		JFB41	Laparoscopic resection of transverse colon
		JFB43	Left hemicolectomy
		JFB44	Laparoscopic left hemicolectomy
		JFB46	Resection of sigmoid colon
		JFB47	Laparoscopic resection of sigmoid colon
		JFB50	Other resection of colon
		JFB51	Other laparoscopic resection of colon

		JFB53	Resection of sigmoid colon with partial proctectomy
		JFB54	Laparoscopic resection of sigmoid colon with partial proctectomy
		JFB60	Resection of sigmoid colon with end colostomy
		JFB61	Laparoscopic resection of sigmoid colon with end colostomy and closure of distal stump
		JFB63	Other resection of colon with proximal colostomy and closure of distal stump
		JFB64	Other laparoscopic resection of colon with proximal colostomy and closure of distal stump
		JFB96	Other partial excision of intestine
		JFB97	Other laparoscopic partial excision of intestine
<b>JFC</b>	Anastomosis of intestine	JFC10	Ileotransversostomy
		JFC11	Laparoscopic ileotransversostomy
		JFC20	Other enterocolostomy
		JFC21	Other laparoscopic enterocolostomy
		JFC30	Colo-colostomy
		JFC31	Laparoscopic colo-colostomy
		JFC40	Ileorectostomy
		JFC41	Laparoscopic ileorectostomy
		JFC50	Colorectostomy
		JFC51	Laparoscopic colorectostomy
<b>JFF</b>	Exteriorisation of intestine and creation of intestinal stomas	JFF10	Loop enterostomy
		JFF13	Terminal enterostomy
		JFF11	Laparoscopic loop enterostomy
		JFF23	Transversostomy
		JFF26	Sigmoidostomy
		JFF27	Laparoscopic sigmoidostomy
		JFF30	Other colostomy
		JFF31	Other laparoscopic colostomy
<b>JFH</b>	Total colectomy	JFH00	Total colectomy and ileorectal anastomosis
		JFH01	Laparoscopic colectomy with ileorectal anastomosis
		JFH10	Total colectomy and ileostomy
		JFH11	Laparoscopic colectomy
		JFH20	Proctocolectomy and ileostomy
		JFH30	Total colectomy, mucosal proctectomy and ileoanal anastomosis without ileostomy
		JFH31	Laparoscopic total colectomy, mucosal proctectomy and ileoanal anastomosis without ileostomy
		JFH33	Total colectomy, mucosal proctectomy, ileoanal anastomosis and ileostomy
		JFH40	Proctocolectomy and continent ileostomy
		JFH96	Other total colectomy
<b>JGA</b>	Proctotomy and local operations on rectum	JGA58	Endoscopic insertion of prosthetic tube into rectum
		JGA73	Transanal excision of lesion of rectum
<b>JGB</b>	Excision of rectum	JGB03	Partial proctectomy with partial excision of mesorectum
		JGB04	Laparoscopic partial proctectomy with partial excision of mesorectum
		JGB06	Partial proctectomy with total excision of mesorectum
		JGB07	Laparoscopic partial proctectomy with total excision of mesorectum

	JGB10	Partial proctectomy and end colostomy
	JGB11	Laparoscopic partial proctectomy and end colostomy
	JGB20	Partial rectosigmoidectomy and abdominoperineal pull-through anastomosis
	JGB30	Abdominoperineal excision of rectum
	JGB31	Laparoscopic and perineal excision of rectum
	JGB36	Wide excision of rectum
	JGB37	Laparoscopic wide excision of rectum

### Surgical treatment of other cancers subject to follow-up

Surgical treatment procedures of other cancers subject to follow-up – cancer of the head and neck area, stomach, pancreas, lungs and trachea; melanoma, corpus uteri, ovaries, testicles, kidneys, bladder and urinary tract, brain and central nervous system, and lymphomas – are listed in table 7.

**Table 7. Surgical procedures of other cancers subject to follow-up**

ICD-10 codes for cancers of the head and neck area beginning with C00-C14 and C30-C32			
	Name of the group	Code	Procedure
		DJW00	Removal of local lesion of nasal septum
		DMB10	Radical maxillary antrotomy
		DMB30	Transmaxillary excision of lesion of maxillary antrum
		DMB40	Excision of lesion of maxillary antrum through lateral rhinotomy
		DMW99	Other operation on maxillary antrum
		DNB30	Excision of lesion of ethmoidal sinus
		DNW99	Other operation on ethmoidal sinus and bone
		DPB10	Partial excision of sphenoidal sinus
		DQB10	Endoscopic excision of lesion of larynx
		DQB20	Partial excision of larynx
		DQB30	Laryngectomy
		DQB60	Arytenoidectomy
		DQB70	Total excision of vocal cord
<b>EAA</b>	Incision and excision of lip	EAA10	Excision of lesion of lip
		EAA20	Partial excision of upper lip
		EAA30	Partial excision of lower lip
<b>ECA</b>	Incision, biopsy and excision of gingiva and alveolus	ECA30	Excision of lesion of gingiva
		ECA35	Complicated excision of lesion of gingiva
<b>EDB</b>	Excision of mandible	EDB00	Partial excision of mandible
		EDB10	Mandibulectomy
		EDB20	Hemimandibulectomy
		EDB99	Other excision on mandible
<b>EDW</b>	Other operations on mandible	EDW99	Other operation on mandible
<b>EEB</b>	Excision of maxilla	EEB00	Partial excision of maxilla
		EEB10	Maxillectomy
		EEB20	Hemimaxillectomy
		EEB99	Other excision of maxilla

<b>EHB</b>	Excision of palate	EHB00	Excision of lesion of palate
<b>EHW</b>	Other operations on palate	EHW99	Other operation on palate
<b>EJB</b>	Excision of tongue and floor of mouth	EJB10	Excision of lesion of apex or body of tongue
		EJB20	Excision of lesion of base of tongue
		EJB30	Excision of lesion of floor of mouth
		EJB40	Hemiglossectomy
		EJB50	Total glossectomy
		EJB60	Partial excision of floor of mouth
		EJB99	Other excision on tongue and floor of mouth
<b>EJW</b>	Other operations on tongue and floor of mouth	EJW99	Other operation on tongue or floor of mouth
<b>EKB</b>	Excision of cheek	EKB00	Excision of lesion of cheek
		EKW99	Other operation on cheek
<b>ELB</b>	Excision of salivary gland	ELB00	Excision or exploration of lesion of salivary gland
		ELB30	Excision of submandibular gland
		ELB40	Partial parotidectomy
		ELB50	Total parotidectomy
<b>EMB</b>	Excision of tonsils and adenoids	EMB00	Excision of lesion of tonsil or adenoids
<b>ENB</b>	Excision of pharynx and adjacent structures	ENB00	Excision or exploration of lesion of pharynx
		ENB20	Pharyngectomy
		ENB30	Laryngopharyngectomy
		ENB99	Other excision of pharynx and adjacent structures
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD51	Block dissection of cervical lymph nodes
		PJD71	Extended sparing excision of cervical lymph nodes
		PJD81	Excision of lymph nodes from upper part of neck
<b>ICD-10 codes for stomach cancer beginning with C16</b>			
<b>JDC</b>	Partial gastrectomy	JDC00	Partial gastrectomy and gastroduodenostomy
		JDC10	Partial gastrectomy and gastrojejunostomy
		JDC11	Laparoscopic partial gastrectomy and gastrojejunostomy
		JDC20	Partial gastrectomy and Roux-en-Y reconstruction
		JDC40	Partial gastrectomy and oesophagogastrostomy
		JDC96	Partial gastrectomy with other reconstruction
		JDC97	Laparoscopic partial gastrectomy with other reconstruction
<b>JDD</b>	Total gastrectomy	JDD00	Total gastrectomy and Roux-en-Y oesophagojejunostomy
		JDD96	Total gastrectomy with other reconstruction
<b>JDW</b>	Other operations on stomach and duodenum	JDW98	Other transluminal endoscopic operation on stomach or duodenum
<b>JFA</b>	Local operations on intestine	JFA65	Endoscopic insertion of ileum stent
<b>JFC</b>	Anastomosis of intestine	JFC20	Other enterocolostomy

<b>ICD-10 codes for pancreatic cancer beginning with C25</b>			
<b>JKD</b>	Biliodigestive anastomosis without excision	JKD10	Anastomosis of bile duct to duodenum
		JKD20	Anastomosis of bile duct to jejunum
		JKD30	Extrahepatic anastomosis of right or left hepatic duct to jejunum
<b>JKE</b>	Transduodenal operations on bile duct or ampulla of Vater	JKE02	Transduodenal endoscopic incision of common bile duct orifice
		JKE18	Endoscopic internal drainage of bile duct
		JKE25	Endoscopic external drainage of bile duct
		JKE32	Endoscopic dilatation of bile duct
		JKE98	Other transduodenal endoscopic operation on bile duct or ampulla of Vater
<b>JKW</b>	Other operations on biliary tract	JKW98	Other transluminal endoscopic operation on biliary tract
<b>JLB</b>	Incision, drainage or dilatation of pancreas	JLB12	Transduodenal endoscopic incision of pancreatic duct orifice
		JLB28	Endoscopic internal drainage of pancreatic duct
		JLB42	Transduodenal endoscopic dilatation of pancreatic duct
<b>JLC</b>	Excision of pancreas	JLC10	Distal pancreatectomy
		JLC11	Laparoscopic distal pancreatectomy
		JLC30	Pancreatoduodenectomy
		JLC40	Total pancreatoduodenectomy
		JLC50	Atypical pancreatectomy
<b>JLW</b>	Other operations on pancreas	JLW98	Other transluminal endoscopic operation on pancreas
<b>ICD-10 codes for lung and tracheal cancers beginning with C33-34</b>			
<b>GBC</b>	Resection and reconstruction of trachea	GBC03	Resection of trachea
		GBC10	Resection and reconstruction of carina
<b>GDB</b>	Minor resections of lung	GDB10	Wedge resection of lung
		GDB11	Thoracoscopic wedge resection of lung
		GDB20	Segmental resection of lung
		GDB21	Thoracoscopic segmental resection of lung
		GDB96	Other minor resection of lung
<b>GDC</b>	Lobectomy of lung	GDC00	Lobectomy of lung
		GDC01	Thoracoscopic lobectomy of lung
		GDC10	Bilobectomy of lung
		GDC11	Thoracoscopic bilobectomy of lung
		GDC13	Extended lobectomy or bilobectomy of lung
		GDC20	Lobectomy of lung and sleeve resection of bronchus
		GDC23	Lobectomy and segment resection of lung
<b>GDD</b>	Pneumonectomy	GDD00	Pneumonectomy
		GDD01	Thoracoscopic pneumonectomy
		GDD20	Extended pneumonectomy
		GDD23	Pneumonectomy and resection of carina
		GDD26	Pneumonectomy and resection of bronchus or bronchus and trachea

ICD-10 codes for melanoma beginning with C43			
<b>CBB</b>	Excision or destruction of lesion of eyelid	CBB30	Excision of lesion of eyelid
		CBB50	Excision of lesion of eyelid and reconstruction using graft or flap
<b>DAB</b>		DAB00	Excision of lesion of auricle
		DAB10	Partial excision of auricle
<b>ELB</b>	Excision of salivary gland	ELB40	Partial parotidectomy
		ELB50	Total parotidectomy
<b>NDQ</b>	Amputations and related operations in wrist and hand	NDQ20	Amputation of finger
<b>NHQ</b>	Amputations and related operations on ankle and foot	NHQ40	Amputation of toe
<b>PJA</b>	Exploration of lymph nodes	PJA12	Sentinel node biopsy
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD41	Excision of cervical lymph nodes
		PJD42	Excision of axillary lymph nodes
		PJD45	Excision of inguinal lymph nodes
		PJD51	Block dissection of cervical lymph nodes
		PJD52	Block dissection of axillary lymph nodes
		PJD54	Block dissection of iliac lymph nodes
		PJD55	Block dissection of inguinal lymph nodes
		PJD71	Extended sparing excision of cervical lymph nodes
		PJD81	Excision of lymph nodes from upper part of neck
		PJD99	Excision of other lymph nodes
<b>PXA</b>	Extracorporeal circulation of different vascular sites	PXA00	Extracorporeal circulation of upper extremity using heart-lung assist device
		PXA20	Extracorporeal circulation of lower extremity using heart-lung assist device
<b>QAE</b>	Excision and repair of lesion of skin of head and neck	QAE10	Excision of other lesion extending through all layers of skin in head or neck
		QAE99	
<b>QBE</b>	Excision and repair of lesion of skin of trunk	QBE10	Excision of other lesion extending through all layers of skin of trunk
		QBE99	Other excision or repair of lesion of skin of trunk
<b>QCE</b>	Excision and repair of lesion of skin of upper limb	QCE10	Excision of other lesion extending through all layers of skin in upper limb
		QCE99	Other excision or repair of lesion of skin of upper limb
<b>QDE</b>	Excision and repair of lesion of skin of lower limb	QDE10	Excision of other lesion extending through all layers of skin in lower limb
		QDE99	Other excision or repair of lesion of skin of lower limb
<b>QXE</b>	Excision and repair of lesion of skin	QXE10	Excision of other lesion extending through all layers of skin in unspecified region
		QXE99	Other excision or repair of unspecified region of skin

ICD-10 codes for endometrial cancer beginning with C54			
<b>LCD</b>	Total excision of uterus	LCD01	Total laparoscopic hysterectomy
		LCD00	Hysterectomy
		LCD04	Laparoscopic hysterectomy
		LCD10	Vaginal hysterectomy
		LCD11	Laparoscopically assisted vaginal hysterectomy
		LCD97	Other laparoscopic hysterectomy
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD53	Block dissection of aortic lymph nodes
		PJD54	Block dissection of iliac lymph nodes
		PJD63	Laparoscopic dissection of aortic lymph nodes
		PJD64	Laparoscopic dissection of iliac lymph nodes
ICD-10 codes for ovarian cancer beginning with C56, C57.0-8			
<b>LAF</b>	Excision of ovary and Fallopian tube	LAF00	Unilateral salpingo-oophorectomy
		LAF10	Bilateral salpingo-oophorectomy
		LAF11	Laparoscopic bilateral salpingo-oophorectomy
		LAF16	Excision of uterus, adnexes and lymph nodes for treatment of ovarian cancer
		LAF17	Laparoscopic excision of uterus, adnexes and lymph nodes for treatment of ovarian cancer
<b>LAE</b>	Total excision of ovary	LAE10	Unilateral oophorectomy
		LAE11	Unilateral laparoscopic oophorectomy
		LAE20	Bilateral oophorectomy
		LAE21	Bilateral laparoscopic oophorectomy
<b>JAH</b>	Opening of peritoneal cavity	JAH00	Laparotomy
		JAH01	Laparoscopy
<b>JAQ</b>	Extensive excision of peritoneum and related procedures	JAQ00	Extensive excision of peritoneum
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD53	Block dissection of aortic lymph nodes
		PJD54	Block dissection of iliac lymph nodes
		PJD63	Laparoscopic dissection of aortic lymph nodes
		PJD64	Laparoscopic dissection of iliac lymph nodes
ICD-10 codes for testicular cancer beginning with C62			
<b>KFA</b>	Exploration and incision of scrotum and scrotal organs	KFA00	Exploration of testis
<b>KFC</b>	Total excision of testis and epididymis	KFC00	Unilateral orchiectomy
<b>KFD</b>	Partial excision of scrotal organs	KFD00	Partial excision of testis
<b>PJA</b>	Exploration of lymph nodes	PJA10	Exploration of lymph nodes
<b>PJD</b>	Excision and block dissection of lymph nodes	PJD53	Block dissection of aortic lymph nodes
		PJD54	Block dissection of iliac lymph nodes
		PJD63	Laparoscopic dissection of aortic lymph nodes
		PJD64	Laparoscopic dissection of iliac lymph nodes



<b>ICD-10 codes for kidney cancer beginning with C64</b>			
<b>KAC</b>	Total excision of kidney	KAC10	Total nephrectomy with capsule
		KAC11	Total nephrectomy with capsule, transcutaneous
<b>KAD</b>	Partial excision or destruction of tumour of kidney and pelvis of kidney	KAD00	Partial nephrectomy
		KAD01	Percutaneous endoscopic partial nephrectomy
		KAD10	Heminephrectomy
		KAD60	Percutaneous destruction of lesion of renal parenchyma
<b>ICD-10 codes for bladder and urinary tract cancers beginning with C65-68</b>			
<b>KAC</b>	Total excision of kidney	KAC20	Nephroureterectomy
		KAC21	Percutaneous endoscopic nephroureterectomy
<b>KBD</b>	Partial excision of ureter and destruction of tumour of ureter	KBD00	Partial excision of ureter
		KBD20	Destruction of tumour of ureter
		KBD21	Percutaneous endoscopic destruction of tumour of ureter
		KBD22	Retrograde ureteroscopic destruction of tumour of ureter
<b>KCC</b>	Total excision of bladder	KCC00	Cystectomy
		KCC10	Cystoprostatectomy
		KCC20	Cystoprostatectomy
		KCC30	Cystectomy with excision of female internal genital organs
		KCC96	Other cystectomy
<b>KCD</b>	Partial excision of bladder and destruction of tumour of bladder	KCD02	Transurethral resection of bladder
		KCD05	Removal of lesion from urinary bladder during cystoscopy using photodynamic diagnostics (PDD)
		KCD10	Partial cystectomy
		KCD30	Destruction of tumour of bladder
		KCD32	Cystoscopic destruction of tumour of bladder
<b>KDC</b>		KDC00	Urethrectomy
<b>KDD</b>		KDD00	Partial excision of urethra
		KDD30	Destruction of tumour of urethra
<b>ICD-10 codes for brain and central nervous system cancer beginning with C70-72, C75.1-3</b>			
<b>AAB</b>	Excision and destruction of intracranial lesion	AAB00	Extirpation of intracranial lesion
		AAB10	Partial excision of intracranial lesion
<b>ABB</b>	Operations for lesions of spinal cord and nerve roots	ABB00	Excision of lesion of spinal canal
		ABB10	Resection of lesion of spinal canal
<b>ICD-10 codes for lymphomas beginning with C81-85</b>			
<b>JMA</b>	Partial splenectomy	JMA10	Transabdominal total splenectomy
		JMA11	Laparoscopic total splenectomy
		JMA20	Transthoracic total splenectomy

### 4.5.3 Instructions for recording chemotherapies

#### General chemotherapy recording principles

**Planning of intervention or health care consultation WZC00** is recorded for appointments with various specialists for the purpose of planning chemotherapy

- in connection with the first planning visit, when treatment plans change (e.g. planning of the second course of treatment or change of chemotherapy for progressive cancer), when making a decision to adopt active surveillance as the line of treatment, and when starting palliative treatment.

#### Recording chemotherapy procedure codes

- **Individual oral and injected chemotherapies** are recorded as procedures carried out during the doctor's appointment at which the treatment is planned. The procedures to be recorded are 'Planning of intervention or health care consultation' WZC00, and the chemotherapy prescribed (codes listed in tables 8-10).
  - Oral and injected chemotherapies are recorded as administered treatment procedures at any first treatment appointments with a nurse, and at each appointment with a nurse or doctor during which the chemotherapy is reviewed.
  - Injected therapies are recorded as administered treatment procedures after the injection.
- **For infusion therapies**, the doctor determines the procedure code during the treatment planning appointment. The procedure recorded for the planning appointment is 'Planning of intervention or health care consultation' WZC00. The nurse records the administration of chemotherapy during the planning appointment in accordance with the doctor's instructions.

**Chemotherapies involving combinations of pharmaceutical substance groups are recorded with separate procedure codes.** These procedure codes are recorded for all treatment days during an inpatient stay, even if only one drug was administered at the time in question. If chemotherapy administered over the course of several days includes antibody therapy, the procedure code for antibody therapy is recorded for the day on which it was administered. The order in which procedure codes for chemotherapy are recorded is irrelevant to reporting related to access to care.

#### Examples of recording practices

##### Intravenous adjuvant chemotherapy for colorectal cancer

- The procedure code recorded in connection with the first appointment is WZC00, and information on the the planned chemotherapy is entered in the text section.
- The chemotherapy procedure code (e.g. WB113, CAPOX) is recorded for the days on which infusion therapy was given.

##### Oral adjuvant chemotherapy for colorectal cancer

- In connection with the first visit, procedure code WZC00 is recorded, as is the chemotherapy procedure code (e.g. WB103 capecitabin).
- In connection with doctor's or nurse's appointments or telephone consultations in which the continuity of chemotherapy is discussed and/or a new treatment cycle is begun, the chemotherapy procedure code is recorded (e.g. WB103 cabecitabin).

**Neoadjuvant chemotherapy for HER-2 positive breast cancer**

- The procedure code recorded in connection with the first appointment is WZC00, and information on the the planned chemotherapy is entered in the text section.
- Procedure codes (e.g. WB610 pertuzumab and trastuzumab combination therapy and WB121 docetaxel) are recorded for infusion administration days.

**Neoadjuvant hormone therapy for prostate cancer before radiotherapy**

- The procedure code recorded in connection with the first appointment is WZC00, and the procedure code WB221 is recorded for the LHRH analogue neoadjuvant therapy.
- The procedure code WB221 is also recorded for appointments or telephone consultations during which the continuity of chemotherapy is discussed, and after the completion of chemotherapy.

**Prostate cancer with bone metastases**

- The procedure code recorded in connection with the first appointment is WZC00, and the procedure code WD225 is recorded for the LHRH analogue treatment and procedure code WD305 for bone medication.
- Procedure codes WD225 and WD305 are also recorded for appointments or telephone consultations during which changes are made to the chemotherapy, and after the administration of each course of chemotherapy.

**Oral treatment of advanced kidney cancer**

- The procedure code recorded in connection with the first appointment is WZC00, and the procedure code WD505 is recorded for oral tyrosine kinase inhibitor therapy.
- The procedure code WD505 is also recorded in connection with a doctor's or nurse's appointments or telephone consultations, during which changes are made to the chemotherapy or a new course of treatment is begun.

**Intravenous treatment of advanced kidney cancer**

- The procedure code recorded in connection with the first appointment is 'Treatment planning or consultation' WZC00, and information on the planned chemotherapy is entered in the text section.
- The procedure code (e.g. WD325 nivolumab) is recorded for the days on which infusion therapy was given.

**Adjuvant chemotherapy for testicular cancer**

- The procedure code recorded in connection with the first appointment is 'Treatment planning or consultation' WZC00, and information on the planned chemotherapy is entered in the text section.
- The chemotherapy procedure code (e.g. WB113 BEP) is recorded for each day on which infusion therapy was given.

**Chemotherapy for advanced cancer of the head and neck area**

- The procedure code recorded in connection with the first appointment is 'Treatment planning or consultation' WZC00, and information on the planned chemotherapy is entered in the text section.
- The chemotherapy procedure code (e.g. WD125 cisplatin and fluorouracil) is recorded for each day on which infusion therapy was given, and, if required, the procedure code for the administration of an antibody (e.g. WD405 cetuximab).

## Treatment of the primary and local tumour

The drugs to be used are recorded with codes listed in table 8. Adjuvant therapy is additional treatment, such as chemotherapy given in addition to cancer surgery, with the objective of destroying any micrometastases. Neoadjuvant therapy for cancer is given before an operation.

When treatment of high risk local prostate cancer is initiated with hormonal therapy, and radiotherapy is not planned because of patient's condition or other reasons, the procedure codes for adjuvant therapy shall be used

- WB203 Simple adjuvant hormone therapy of malignancy, bicalutamid
- WB223 Demanding adjuvant hormone therapy of malignancy, LHRH agonists

**Table 8. Procedure codes used in the drug treatment of a primary/local tumour**

Adjuvant therapy		
Code	Procedure	Drugs used
WB103	Simple adjuvant cytostatic therapy	Single-agent chemotherapy, e.g. docetaxel
WB113	Multiple adjuvant cytostatic therapy	Combination chemotherapy, e.g. CEF, XELOX
WB203	Simple adjuvant hormone therapy of malignancy	Aromatase inhibitors, tamoxifen
WB223	Demanding adjuvant hormone therapy of malignancy	LHRH analogues
WB401	Simple antibody therapy of primary tumour	Antibody therapy with a single agent, such as trastuzumab
WB402	Demanding antibody therapy of primary tumour	Combination antibody therapy, such as pertuzumab & trastuzumab
WB303	Simple adjuvant therapy of malignancy with biomodifiers	Interferon
WB323	Demanding adjuvant therapy of malignancy with biomodifiers	Ipilimumab, nivolumab, pembrolizumab
WB501	Simple enzyme inhibitor or similar therapy of primary tumour	Imatinib
Neoadjuvant therapy		
WB121	Demanding neoadjuvant cytostatic therapy	Preoperative chemotherapy
WB201	Simple neoadjuvant hormone therapy of malignancy	Aromatase inhibitors
WB221	Demanding neoadjuvant hormone therapy of malignancy	LHRH analogues
WB321	Multiple adjuvant therapy of malignancy with biomodifiers	
WB600*	Neoadjuvant therapy of primary tumour with antibodies	
WB610*	Demanding neoadjuvant therapy of tumour with antibodies	

\* Classification will be supplemented; this code will be available for use in 2017

## Treatment of a locally recurrent tumour

The drugs to be used are recorded with codes listed in table 9. No distinction is required between adjuvant and neoadjuvant therapies in the treatment of recurrent tumours.

**Table 9. Procedure codes used in the chemotherapy of a locally recurrent tumour**

Adjuvant and neoadjuvant therapies		
Code	Procedure	Drugs used
WC105	Simple cytostatic therapy of local tumor recidive	Single-agent chemotherapy, e.g. docetaxel,
WC125	Demanding cytostatic therapy of local tumor recidive	Combination chemotherapy, e.g. CEF, CAPOX
WC205	Simple therapy of local tumor recidive with hormone	Aromatase inhibitors, tamoxifen
WC225	Demanding therapy of local tumor recidive with hormone	LHRH analogues
WC305	Simple therapy of local tumor recidive with biomodifiers	Interferon
WC325	Demanding therapy of local tumor recidive with biomodifiers	Ipilimumab, nivolumab, pembrolizumab
WC401	Simple antibody therapy of local recurrence of tumour	Single-agent antibody therapy, e.g. trastuzumab
WC402	Demanding antibody therapy of local recurrence of tumour	Combination antibody therapy, such as pertuzumab & trastuzumab
WC501	Simple enzyme inhibitor or similar therapy of local recurrence of tumour	Tyrosine kinase inhibitor, e.g. sunitinib, lapatinib

## Chemotherapy for metastatic cancer

Drugs used for the treatment of metastatic cancer are recorded with codes listed in table 10. Treatment given for lymphomas is recorded using the procedure codes for metastatic cancer.

Other combination therapies are recorded using separate codes, such as:

- Bevacizumab and CAPOX: WD125 and WD405
- Pertuzumab, trastuzumab and docetaxel WD105 and WD415

**Table 10. Procedure codes used in the drug treatment of metastatic cancer**

Drug treatment of metastatic cancer		
Code	Procedure	Drugs used
WD105	Cystostatic therapy of methastized malignancy	Single-agent chemotherapy (oral and injected), e.g. docetaxel, capecitabine
WD125	Demanding cystostatic therapy of methastized malignancy	Combination chemotherapy, e.g. CEF, CAPOX and oral combination chemotherapy such as capecitabine & temozolimide
WD205	Therapy of methastized malignancy with hormones	E.g. aromatase inhibitors, tamoxifen, bicalutamide, abiraterone, enzalutamide
WD225	Demanding therapy of methastized malignancy with hormones	E.g. LHRH analogues, fulvestrant
WD305	Simple therapy of methastized malignancy with biomodifiers	E.g. interferon, zoledronic acid and denosumab
WD325	Demanding therapy of methastized malignancy with biomodifiers	Immunological drugs such as ipilimumab, nivolumab, pembrolizumab
WD405	Simple antibody therapy of methastized malignancy	Single-agent antibody therapy, e.g. Trastuzumab, rituximab, bevacizumab
WD415	Demanding antibody therapy of methastized malignancy	Combination antibody therapy and antibody therapy in combination with chemotherapy, such as pertuzumab & trastuzumab, trastuzumab emtancine
WD505	Simple enzyme inhibitor or similar therapy of methastized malignancy	Tyrosine kinase inhibitor as a single agent, e.g. sunitinib, erlotinib, lapatinib

#### 4.5.4 Instructions for recording radiotherapy

##### General radiotherapy recording principles

**Planning of intervention or health care consultation WZC00** is recorded for doctor's appointments for the purpose of planning radiotherapy. Descriptive procedure code(s), or Y code(s), are recorded according to the instructions given by each centre.

**The doctor determines the radiotherapy procedure code**, or the code describing the objective or stage of the treatment, or the stage of the cancer (table 11), in connection with a visit to assess the treatment or to prescribe radiotherapy. These include procedure codes beginning with WF0, HA0, WA0 and XX7, and also codes AX099 and QX099.

- If several areas are treated with different dose plans during the same treatment cycle, the corresponding number of procedure codes must be recorded. Procedure codes are recorded in connection with each radiotherapy visit.

**The radiotherapy planning work code** is XX3DW (Time consuming IT work) and it is recorded on the first day of each course of radiotherapy treatment. Code XX3DW will be recorded twice if two separate areas are treated during the same course of treatment. If an entirely new dose plan is prepared during one inpatient stay, code XX3DW will be recorded when treatment with the new plan begins.

Procedure codes describing the **radiation technology** used (prefix ZX0) should be recorded according to the instructions provided by each centre.

- The procedure code for stereotactic radiotherapy is ZX050 regardless of the area being treated or the stage of treatment (curative/palliative). Please note that ZX is a so-called additional code and always requires a main procedure code. For instance, the main code for the treatment of metastasis is WF049.
- **Chemoradiotherapy** procedure code is ZX095.

**The procedure codes for cancer drugs used in chemoradiotherapy** are those listed for adjuvant therapies: WB103, WB113-WB223 and WB401 (table 11).

- The doctor determines the procedure code for the cancer drug and is recorded in the same way as any other chemotherapy (see section 4.5.3).

##### Examples of recording practices

**Breast cancer:** Radiotherapy for a patient undergone partial mastectomy

- The procedure code recorded in connection with the first appointment is WZC00. During this visit, or when prescribing radiotherapy, information regarding the planned radiotherapy is entered in the text section.
- The Y code describing the visit involving the planning of the radiotherapy is recorded in accordance with the centre's own practices.
- The radiotherapy planning work code XX3DW is recorded during the first treatment session.
- The radiotherapy procedure code HA003 is recorded for each radiotherapy treatment visit.
- The ZX technology codes are recorded according to the centre's own practices.

**Rectal cancer:** Preoperative chemoradiotherapy

- The procedure code recorded in connection with the first appointment is WZC00, and, when required, procedure code WB103 for chemotherapy tablet (e.g. capecitabine). During this visit, or when prescribing radiotherapy, information regarding the planned radiotherapy is entered in the text section.
- The Y code describing the visit involving the planning of the radiotherapy is recorded in accordance with the centre's own practices.
- The radiotherapy planning work code XX3DW is recorded during the first treatment session.
- The chemoradiotherapy code ZX095 is recorded according to the centre's own practices.
- The radiotherapy code WF001 is recorded for each radiotherapy treatment visit.
- The ZX technology codes are recorded according to the centre's own practices.

**Head and neck cancers:** A course of definitive chemoradiotherapy

- The procedure code recorded in connection with the first appointment is 'Planning of intervention or health care consultation' WZC00. During this visit, or when prescribing radiotherapy, information regarding the planned radio or chemotherapy is entered in the text section.
- The Y code describing the visit involving the planning of the radiotherapy is recorded in accordance with the centre's own practices.
- The radiotherapy planning work code XX3DW is recorded during the first treatment session.
- The Y code and XX3DW will be recorded again if the preparation of a new description and a new plan is required during the course of radiotherapy treatment.
- The radiotherapy procedure code WF002 is recorded for each radiotherapy treatment visit.
- The chemoradiotherapy code ZX095 is recorded according to the centre's own practices.
- The ZX technology codes are recorded according to the centre's own practices.
- The unit administering intravenous chemotherapy records WB103 (e.g. cisplatin) every time the drug is administered.

**Prostate cancer:** External radiotherapy combined with hormone therapy

- The procedure code recorded in connection with the first appointment is WZC00. During this visit, or when prescribing radiotherapy, information regarding the planned radiotherapy is entered in the text section. Hormone therapy is recorded as a procedure if it is started or discussed during this appointment.
- The Y code describing the visit involving the planning of the radiotherapy is recorded in accordance with the centre's own practices.
- The radiotherapy planning procedure code XX3DW is recorded during the first treatment session.
- The radiotherapy procedure code WF002 is recorded for each radiotherapy treatment visit.
- The ZX technology codes are recorded according to the centre's own practices.
- Procedure code WB223 is recorded on the day a hormone injection is administered.

**Palliative** radiotherapy for a bone metastasis of lung cancer and the primary tumour, two separate treatment areas.

- The procedure code recorded in connection with the first appointment is WZC00. During this visit, or when prescribing radiotherapy, information regarding the planned radiotherapy is entered in the text section.
- The Y code describing the visit involving the planning of the radiotherapy is recorded in accordance with the centre's own practices.
- The radiotherapy planning procedure code XX3DW x 2 is recorded during the first treatment session.
- Radiotherapy procedure codes WF004 and WF049 are recorded for all radiotherapy visits.
- The ZX technology codes are recorded according to the centre's own practices.



Table 11. Procedure codes used in the radiotherapy of metastatic cancer

Primary tumour/local		
Code	Procedure	More detailed description, examples
WF001	Preoperative radiotherapy	E.g. Preoperative treatment of rectal cancer
WF002	Radical radiotherapy	Definitive treatment in which radiotherapy is provided as the only curative treatment. Examples: <ul style="list-style-type: none"> <li>- Head and neck cancers</li> <li>- All brain tumours (also if radiotherapy is the second-line treatment)</li> <li>- Prostate cancer (including treatment given after active surveillance)</li> <li>- High-dose treatment of acoustic neuroma, meningioma and similar.</li> </ul>
WF003	Adjuvant radiotherapy	Treatment provided in addition to or as part of other curative treatment. Examples: <ul style="list-style-type: none"> <li>- Postoperative and post-cytostatic therapies treatments (for lymphomas)</li> <li>- So-called prophylactic brain radiotherapy for lung cancer (to treat potential micrometastasis)</li> </ul>
HA003	Radiotherapy after partial ablation of mammary gland	Breast and the necessary lymph nodes As an adjuvant therapy to surgery
HA013	Radiotherapy after total ablation of mammary gland	Chest and the necessary lymph nodes As an adjuvant therapy to surgery
Local recurrence of a tumour after radical treatment		
WF029	Radiotherapy of local residue tumor	<ul style="list-style-type: none"> <li>- Radical dose treatment of a recurrent tumour</li> <li>- All repeat/additional radiotherapies, such as salvage treatment for prostate cancer</li> </ul>
Palliative treatment of a local tumour		
WF004	Palliative radiotherapy	<ul style="list-style-type: none"> <li>- Local treatment to alleviate the symptoms of the primary disease</li> <li>- Treatment to alleviate the symptoms of a locally recurrent or progressive disease</li> <li>- E.g. lung cancer</li> </ul>
Palliative treatment of advanced cancer		
WF049	Radiotherapy of metastasis	Regardless of the number or location of metastases or areas to be treated <ul style="list-style-type: none"> <li>- The treated area may also cover the primary tumour</li> </ul>
Body radiotherapy		
WA010	Adjuvant whole body radiotherapy	
WA029	Half body radiotherapy	
QX099	Whole skin radiotherapy	
Prophylactic radiotherapy		
WF090	Prophylactic radiotherapy	E.g. Radiotherapy for mammary glands before the start of antiandrogen treatment
Radiotherapy for the central nervous system		
AX099	Radiotherapy of whole central nervous system	

<b>Other radiotherapy</b>		
<b>WF099</b>	Other radiotherapy	E.g. Low-dose therapy for lymph nodes
<b>Chemoradiotherapy and drug codes</b>		
<b>ZX095</b>	Combined chemoradiotherapy	
WB103	Simple adjuvant cytostatic therapy	E.g. capecitabine, cisplatin
WB113	Multiple adjuvant cytostatic therapy	E.g. Combination therapy with cisplatin and fluorouracil
WB223	Demanding adjuvant hormone therapy of malignancy	E.g. LHRH analogue (NB. Start of neoadjuvant therapy WB221)
WB401	Simple antibody therapy of primary tumour	E.g. cetuximab
<b>Radioisotope therapies</b>		
<b>XX7AT</b>	Radiation therapy with Radium-223	
<b>XX7CT</b>	Radioiodine therapy of thyroid tissue	
<b>XX7FT</b>	Radioyttrium therapy with connected antibody	
<b>XX7GT</b>	Selective internal radio therapy (SIRT) with Yttrium	
<b>XX7JT</b>	Somatostatin isotope ablative therapy	
<b>XX7KT</b>	Radiosamarium therapy	

#### 4.5.5 Instructions for recording other procedures

Other procedures associated with cancer therapies, such as stem cell transplantation and various local treatments of tumours or abnormal tissue, such as laser therapies.

**Table 12. Codes for other procedures used in the treatment of cancer**

<b>Stem cell transplant</b>		
<b>Code</b>	<b>Procedure</b>	
<b>WW300</b>	Transfer of autologic stem cells	
<b>WW302</b>	Allogenic transfer of stem cells from relative	
<b>WW304</b>	Transfer of stem cells from registered domestic donator	
<b>WW306</b>	Transfer of stem cells from foreign registered donator	
<b>WW310</b>	Transfer of stem cells from cord blood	
<b>Local treatment of tumour or abnormal tissue</b>		
<b>GBA25</b>	Endoscopic electrocoagulation of lesion of trachea	
<b>GBA28</b>	Endoscopic laser therapy of lesion of trachea	
<b>JJA43</b>	Destruction of lesion of liver	
<b>JJA44</b>	Laparoscopic destruction of lesion of liver	
<b>XX6DT</b>	Embolization of other tumour with radiological guidance	
<b>XX6LT</b>	Coagulation of tumour with radiological guidance	
<b>TJJ10</b>	Percutaneous destruction of lesion of liver	
<b>JN4NT</b>	Coagulation of tumour in trunk with radiological guidance	

## 5 Submitting the data

Data is submitted as instructed in the Hilmo guide, because the data is collected for the Hilmo register. As of the beginning of 2017, this data can be submitted to the National Institute for Health and Welfare (THL) once a month.

## 6 Reporting

Information on the actual waiting times of patients diagnosed with cancer will be available on THL's website as soon as the quality of the data reaches an acceptable level.

Reports will be updated monthly as soon as hospitals are able to submit monthly data to the Hilmo register. The waiting period for access to care will be determined on the basis of actual treatment periods, in which case data regarding the arrival of the cancer patient's referral, doctor's appointment and placement on a waiting list will be retrieved retroactively.

For all types of cancers included in the follow-up system, data will be grouped by the patient's residence and the service provider.

The indicators used to describe the general situation (from arrival of referral to the first appointment with a doctor, and from placement on the waiting list to the first treatment) are as follows:

- Less than 2 weeks
- 2 – 4 weeks
- More than 4 but no more than 6 weeks
- More than 6 but no more than 8 weeks
- More than 8 but no more than 12 weeks

It should be noted that these times are not recommendations; they are only provided for purposes of comparison.

Instead, the times referred to in this guide regarding the treatment of breast, prostate and colorectal cancers are recommended maximum times (figures 2-5 on pages 18-19) within which treatment should be given.

Compliance with recommendations can be assessed on the basis of actual waiting times before access to care, and the recommendations can then be changed and supplemented as necessary.

## References

- Development of cancer prevention, early detection and rehabilitative support 2014–2025. National Cancer Plan, Part II Directions 6/2014. National Institute for Health and Welfare (THL)  
Available: <http://urn.fi/URN:ISBN:978-952-302-185-3>.
- Finnish breast cancer group 2015. Rintasyövän valtakunnallinen diagnostiikka- ja hoitosuositus 2015  
Available: <http://rintasyoparyhma.yhdistysavain.fi/hoitosuositus>
- Hilmo 2016. HILMO - Sosiaalihuollon ja terveydenhuollon hoitoilmoitus - Määrittelyt ja ohjeistus. Voimassa 1.1.2017 lähtien. Directions 16/2016, National Institute for Health and Welfare (THL).  
Available: <http://urn.fi/URN:ISBN:978-952-302-690-2>
- Komulainen, Jorma 2012. Suomalainen tautien kirjaamisen ohjekirja. National Institute for Health and Welfare (THL)  
Available: <http://urn.fi/URN:ISBN:978-952-245-511-6>
- Monitrering af forløbstider på kræftområdet. Sundhedsstyrelsen, Danish Health and Medicines Authority  
Available: <http://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/monitoreringer/kræft>
- Mäklin, Suvi ja Mäkelä, Marjukka 2008. Hoitoon pääsy syöpätaudeissa: Kysely sairaanhoitopiireille elokuussa 2008. Työpöytäraportti 33/2008. National Research and Development Centre for Welfare and Health (Stakes).  
Available: <http://urn.fi/URN:NBN:fi-fe201204193715>
- Prostate cancer. Current care Guidelines. Working group appointed by Finnish Medical Society Duodecim and the Finnish Urological Association. Helsinki: Finnish Medical Society Duodecim, 2014.  
Available: <http://www.kaypahoito.fi/web/kh/suosituks/suositus?id=hoi11060>
- Statistics of Finnish Cancer Registry.  
Available: <http://www.cancer.fi/syoparekisteri/tilastot>
- STM 2010. Development of cancer treatment in 2010–2020. Working group report. Reports of the Ministry of Social Affairs and Health 2010:6  
Available: <http://urn.fi/URN:ISBN:978-952-00-2971-5>
- STM 2014. Comprehensive Cancer Center Finland (FICAN); Final report by working group on founding of Comprehensive Cancer Center Finland. Reports and Memorandums of the Ministry of Social Affairs and Health 2014:13  
Available: <http://urn.fi/URN:ISBN:978-952-00-3490-0>
- Tautiluokitus ICD-10, 2011. Tautiluokitus ICD-10, 3. painos. Luokitukset, termistöt ja tilasto-ohjeet 5/2011. National Institute for Health and Welfare (THL).  
Available: <http://urn.fi/URN:NBN:fife201205085423>
- Virkkunen Heikki, Mäkelä-Bengs Päivi ja Vuokko Riikka 2015. Manual for structured data entry in health care. Entering essential patient record structures in the electronic patient record – Part I. Directions 2/2015. National Institute for Health and Welfare (THL).  
Available: <http://urn.fi/URN:ISBN:978-952-302-479-3>
- Väntetider i cancervården. Rapport december 2014. Socialstyrelsen 2014-12-11  
Available: <http://www.socialstyrelsen.se/publikationer2014/2014-12-11>.
- Öppna jämförelser 2014. Cancersjukvård, jämförelser mellan landsting. Socialstyrelsen 2014-12-2.  
Available: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19548/2014-12-2.pdf>