

**Bone Metastasis Registry
Manual**

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1 Information about the registry

The Bone Metastasis Registry is a unique international collaboration among well renowned cancer centers. The main interest is to collect patient data that will allow scientific studies of good quality and make international comparisons of treatments and outcome possible.

PATHFx is a clinical decision support tool capable of estimating survival in patients with metastatic bone disease. The tool helps physicians individualize treatments, like whether to offer surgery or not, and whether a more durable and expensive implant may be necessary. This decision support enables highly accurate individual patient treatment decisions, support patient-centered care, improve quality of life and lower healthcare costs.

PATHFx is based on machine learning artificial intelligence technology and is integrated in the Bone Metastasis Registry. This allows us to improve prognostic information, over time, to ensure that PATHFx remains clinically relevant, even as medical therapy and treatment philosophies evolve.

Contact information

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2 Login

To log in you need a Yubikey (a strong two factor authentication device).
Contact rikard.wedin@regionstockholm.se for more information.

1. Go to this web site:
<https://rcc.incanet.se/>

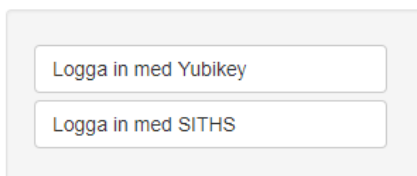


Figure 1 Log in phase

2. Click on the 'Logga in med Yubikey' button.

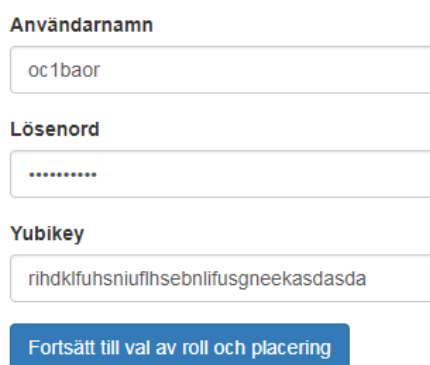
A screenshot of a login form. It contains three input fields and one button. The first field is labeled "Användarnamn" and contains the text "oc1baor". The second field is labeled "Lösenord" and contains a series of dots. The third field is labeled "Yubikey" and contains a long alphanumeric string. Below the fields is a blue button with white text that reads "Fortsätt till val av roll och placering".

Figure 2 Log in phase

3. Enter your username in the 'Användarnamn' field.
Enter your password in the 'Lösenord' field.
Mark the 'Yubikey' field and press the green circle on the Yubikey to generate a one-time password.
If everything is correct you are now logged in.
If you are not automatically logged in, click on the 'Fortsätt till val av roll och placering' button.

3 Start page

The start page consists of three sections (figure 3) as well as two buttons at the very top right of the page (figure 4).

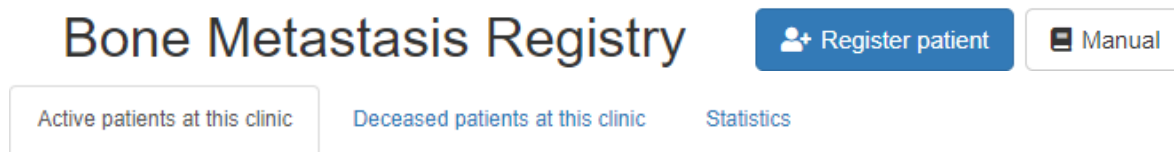


Figure 3 Start page of the registry

1. [Active patients at this clinic](#)
This tab shows a list of all active (living) patients registered at your clinic.
2. [Deceased patients at this clinic](#)
This tab shows a list of all deceased patients registered at your clinic.
3. [Statistics](#)
This tab shows reports and other statistics.
4. [Register patient](#)
Here you register new patients.
If you have already started a registration for a patient, the information is accessed from either the 'Active patients at this clinic' tab or the 'Deceased patients at this clinic' tab. Only start a new registration if it is a completely new patient. Once a patient is registered, they will appear in the either the 'Active patients at this clinic' tab or the 'Deceased patients at this clinic' tab, depending on whether a date of death is registered.
5. [Manual](#)
This is a link to documents about how to register patients (including this document).

3.1 Active patients at this clinic

This is the default tab that is shown when you log in. All patients registered at your clinic are listed here under the following headers (as shown in figure 4).

Identifier: When registering a new patient, a unique code is created. This code is shown here.

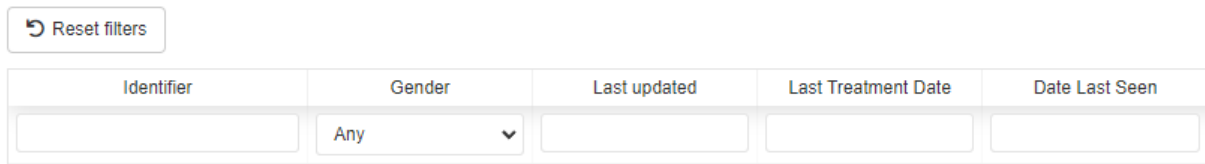
Gender: The gender of the patient. Can either be Female or Male.

Last updated: The date (YYYY-MM-DD) when the information for this patient was last updated (after clicking 'Save').

Last treatment date: The latest date (YYYY-MM-DD) of treatment. If more than one (1) year has passed the date of treatment and no date of death is registered a warning is shown as a reminder to check the registration.

Date last seen: Registered date (YYYY-MM-DD) when the patient was last seen.

Active patient registrations



Identifier	Gender	Last updated	Last Treatment Date	Date Last Seen
<input type="text"/>	Any ▼	<input type="text"/>	<input type="text"/>	<input type="text"/>

Figure 4 The tab 'Active patients at this clinic'

To access the form for the patient, click anywhere in the patient row.

Each header (Identifier, Gender, Last updated, Last Treatment Date and Date Last Seen) can be clicked on to sort the list accordingly. Click again to reverse the order.

Each search field can be used to filter the list. Click in a field and type something followed by [Return] to activate the filter. Multiple fields can be used at the same time.

To clear a search field, remove the text and press [Return]. All registered entries for that header will then be shown again. To clear all filters, click the 'Reset filter' button just over the headers. All registered entries will then show again.

The sorting and filters will be automatically removed when you log out, after which all patients will be visible again.

To access the form for the patient, click the icon at the far right of that patient row.

3.2 Deceased patients at this clinic

Here you can see all deceased patients registered at your clinic. They are listed under the following headers (as shown in figure 5).

Identifier: When registering a new patient, a unique code is created. This code is shown here.

Gender: The gender of the patient. Can either be Female or Male.

Last updated: The date (YYYY-MM-DD) when the information for this patient was last updated (after clicking 'Save').

Date of death: Whether the patient is registered as deceased or not (shows as 'Yes' or 'No').

3.3 Statistics

Here you will find reports and other statistics.

3.4 Register patient

To register a new patient, you need to register a unique identifier. To do this just type in your chosen unique number (with a maximum of four characters) and the rest of the sequence will be filled in automatically (see figure 6).



Register new patient ×

Figure 5 Register patient

To register a new patient, you need to register a unique identifier. To do this just type in your chosen unique four-figure number (NNNN) and the rest of the sequence will be filled in automatically (see figure 5).

In this example, 45 is typed in as the number and then *BoneMet-DMO-1-0045* is shown. If the identifier is already allocated, you will see a warning and the option to either continue registering the already existing patient or cancel the registration (see figure 6).

The patient already has an existing registration in SkeletalMetastases

Identifier: BoneMet-DMO-1-0045

Cancel

Open existing registration

Figure 6 Example of an Identifier already registered.

If you enter a unique Identifier you will see a dialogue window where you can register the date of birth (optional) and gender (mandatory) (see figure 7).

Click 'Continue' to start registering data, or 'Cancel' to remove the registration completely.

See [section 4](#) on how to register data for the patient.

Add new patient (BoneMet-DMO-1-0765) to INCA

No patient with the identifier **BoneMet-DMO-1-0765** was found on INCA. You may create a new patient manually in this step.

Date of birth

Gender

 ▼

Cancel

Continue

Figure 7 Register patient information

3.5 Manual

This is a link to documents about how to register patients (including this document).

4 The form

At the top of the form there is a summary of basic information about the patient. To show/hide the information, click on the grey frame with the Identifier.

Underneath are six tabs where the registration takes place. See each respective chapter below for more information about the variables.

Skeletal metastases registration

♀ , BoneMet-DMO-1-0035

Identifier	BoneMet-DMO-1-0035
Name	
Age	42
Sex	Female

Primary data
Metastases location
Surgery
Radiotherapy
PATHFx
Comments

Figure 8 Example of patient information

4.1 Primary data

Variable	Information
Primary tumor	<p>One of the following must be chosen:</p> <ul style="list-style-type: none"> Breast Lung Prostate gland Kidney Myeloma Lymphoma Liver Gastric Thyroid gland Melanoma Colorectal Bladder Female genital organs Sarcoma Squamous cell carcinoma Unknown Other (free text box will be shown)
Specify type (The list for specifying type depends on which 'Primary tumor' has been selected)	<p>For some of the above primary tumors, you must select a tumor type. One of the following for the respective primary tumor must be chosen:</p> <p style="margin-left: 40px;">Lung: Non-small cell</p> <p style="margin-left: 40px;">Small cell</p> <p style="margin-left: 40px;">Unknown</p>

Variable	Information
Lymphoma:	Lymph node of head, face and neck Intrathoracic lymph nodes Intra-abdominal lymph nodes Lymph nodes of axilla or arm Lymph nodes of inguinal region or leg Pelvic lymph nodes Lymph nodes of multiple regions Lymph node, NOS Unknown
Gastric:	Esophagus Stomach Unknown
Melanoma:	Skin melanoma Connective, subcutaneous and other soft tissues Unknown
Colorectal:	Colon Rectosigmoid junction Rectum Unknown
Female genital organs:	Cervix uteri Corpus uteri Ovary Unknown
Date of birth	Date of birth (YYYY-MM-DD) (voluntary).
Date of diagnosis	Date of diagnosis of the primary tumor (YYYY-MM-DD).
Biological therapy	One of the following must be chosen: Checkpoint inhibition Targeted therapy for a genetic mutation Adaptive immunotherapy Other (free text box will be shown)
Drug / Medicine	Specify drug / medicine
Biological response	One of the following must be chosen: Responder Non-responder Equivocal
Date last seen	Date (YYYY-MM-DD) when the patient was last seen.
Date of death	Date of death of the patient (YYYY-MM-DD).
Cause of death (Only visible if 'Date of death' has a date registered)	One of the following must be chosen: Due to cancer Other reason

4.2 Metastases locations

Press 'Add Location' to start registering the metastasis location (multiple entries can be added). Bone, Bone location and Side must be registered for every location.

For each metastasis location, surgery and radiotherapy are registered later (see [section 4.3](#) and [4.4](#)).

Variable	Information
Bone	The bone receiving metastasis treatment. One of the following must be chosen:

Variable	Information
	Femur Humerus Tibia Pelvis Scapula Spine Other (free text box will be shown)
Bone location (This list will vary according to the 'Bone' selected in the previous section)	One of the following bone locations must be chosen for each previously selected 'Bone'. Femur: Head Neck Intertrochanteric Subtrochanteric Diaphysis Distal Humerus: Head Neck Diaphysis Distal Tibia: Epiphysis Metaphysis Diaphysis Distal Pelvis: Acetabulum Os ileum Os pubis Scapula: Body/Spine Coracoid Acromion Glenoid Spine: Cervical Thoracic Lumbar Other: Proximal Diaphysis Distal Not applicable
Side	For every location, a side must be chosen. Right Left Not applicable
Image	Upload an optional DICOM image for each metastasis location. The image can be removed by clicking 'Remove image'. When the form is saved a link will be created here where the image can be downloaded from.
Image comment	Add an optional comment to the uploaded DICOM image.

4.3 Surgery

If surgery has been performed, this is where you register that information for the relevant metastasis location already registered in [section 4.2](#).

Press 'Add Surgery' or 'Add reoperation' to start registering (multiple entries can be added). A reoperation must be linked to a main surgery and a date for the reoperation must be registered (see figure 10). If there is no main surgery registered, a reoperation cannot be registered.

Select surgery for reoperation ×

Select a surgery and click the button 'Add reoperation' to create a new entry for reoperation.

Main surgery


Date of reoperation
 

Figure 9 Example of a registration of a reoperation.

Variable	Information
Surgeon	Name of the surgeon who performed the surgery.
Surgery date	Date of surgery (YYYY-MM-DD).
Metastasis location link	Choose the relevant metastasis location where surgery has been performed (if this list is empty no location has yet been registered. See section 4.2)
Age at surgery	Age at time of surgery should be entered if not automatically generated.
Patient's BMI	The BMI (Body Mass Index) of the patient.
Metastases at the time of surgery	Click 'Add Metastases' to add types of metastases. Multiple entries can be added. Skeletal is always selected. The following can also be chosen: Brain Liver Lung Lymph node Skeletal Other (free text box will be shown) Unknown
Number of skeletal metastases	Number of skeletal metastases. One of the following must be chosen: Multiple Solitary Unknown
Surgeons estimation of survival pre-surgery (number of months)	Estimation of survival (in months)
Lab Data (click 'Add Lab Data' to register)	
Date	Date of laboratory testing (YYYY-MM-DD).
ALB	Preoperative Albumin (ALB) in g/L, within one week before the procedure; typical range (~34-45). For USA centers in which g/dL is used, multiply by 10 to convert to g/L. For instance, an ALB value of 4 g/dL = 40 g/L
ALP	Preoperative Alkaline Phosphatase (ALP) in U/L, one week before surgery. Typical range (~50-500)

Variable	Information
CRP	Preoperative C-Reactive Protein (CRP) in mg/L, one week before surgery. Typical range (~0–100)
ESR	Preoperative Erythrocyte Sedimentation Rate (ESR) in mm/hour, one week before surgery. Typical range (~0-50)
HB	Preoperative Hemoglobin (HB) in g/L, one week before surgery. Typical range (~50-180). For USA centers in which g/dL is used, multiply by 10 to convert to g/L. For instance, a HB Value of 10 g/dL = 100 g/L
ALC	Preoperative Absolute Lymphocyte Count in 10 ⁹ cells / L, which is equivalent to other units commonly used in the USA such as K/mm ³ or K/ μ L, within one week before the procedure; typical range (~0-9)
Promis (click 'Add Promis' to register)	
Date for Promis	Date of Promis survey (YYYY-MM-DD).
Type	Type of Promis. One of the following must be chosen: Preop One month postop (+- 7 days) Six months postop (+- 14 days) 12 months postop (+- 30 days)
Mobility	Mobility score
Physical Function	Physical function score
Upper Extremity	Upper extremity score
Pain Behavior	Pain behavior score
Pain Inference	Pain inference score
Performance Status (click 'Add Performance Status' to register)	
Date of status	Date of performance status (YYYY-MM-DD).
ASA status	Status per ASA. One of the following must be chosen: 1. A normal healthy patient 2. A patient with mild systemic disease 3. A patient with severe systemic disease 4. A patient with severe systemic disease that is a constant threat to life 5. A moribund patient who is not expected to survive without the operation
ECOG status	Status per ECOG. One of the following must be chosen: 0 Fully active, able to carry on all pre-disease performance without restriction 1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature 2 Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours 3 Capable of only limited selfcare, confined to bed or chair more than 50 % of waking hours 4 Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair. 5 Dead
Karnofsky Status	Status per Karnofsky. One of the following must be chosen: 100 Normal, no complaints

Variable	Information
	<p>90 Able to carry on normal activities. Minor signs or symptoms of disease</p> <p>80 Normal activity with effort</p> <p>70 Care for self. Unable to carry on normal activity or to do active work</p> <p>60 Requires occasional assistance, but able to care for most of their needs</p> <p>50 Requires considerable assistance and frequent medical care</p> <p>40 Disabled. Requires special care and assistance</p> <p>30 Severely disabled. Hospitalisation indicated though death non-imminent</p> <p>20 Very sick. Hospitalisation necessary. Active supportive treatment necessary</p> <p>10 Moribund</p> <p>0 Dead</p>
Surgery	
Main indication	<p>Main indication for surgery. One of the following must be chosen:</p> <p>Complete fracture, non-spinal</p> <p>Impending fracture, non-spinal</p> <p>Complete fracture, neurological compromise</p> <p>Impending fracture, neurological compromise</p> <p>Complete fracture, other reason (free text box will be shown)</p> <p>Impending fracture, other reason (free text box will be shown)</p>
Operation Method	<p>One of the following must be chosen:</p> <p>Hemi prosthesis</p> <p>Prosthesis, total joint replacement</p> <p>Prosthesis & acetabular reconstruct</p> <p>Mega/tumor prosthesis</p> <p>Glide screw plate</p> <p>Plate</p> <p>Recon nail (cervical screw)</p> <p>Intramedullary nail</p> <p>Laminectomy & posterior stabilization</p> <p>Laminectomy & anterior stabilization</p> <p>Laminectomy without stabilization</p> <p>Closed prosthetic reduction (only valid for Reoperation)</p> <p>Other (free text box will be shown)</p>
Reason	<p>The reason for the reoperation. Only valid for reoperation. One of the following must be chosen:</p> <p>Non-union</p> <p>Local tumor progression</p> <p>Stress fracture of bone</p> <p>Poor initial fixation (within 6 wks)</p> <p>Implant failure</p> <p>Technical error</p> <p>Prosthetic dislocation</p> <p>Wound infection</p> <p>Deep infection</p> <p>Other (free text box will be shown)</p>
Operation strategy	<p>One of the following must be chosen:</p>

Variable	Information
	Curettage Curettage + cement Stabilization without tumor removal Excision with wide margins Marginal excision Other (free text box will be shown)
Local adjuvant treatment	One of the following must be chosen: Yes No
Type of adjuvant treatment (Only visible if 'Yes' is chosen for Local adjuvant treatment)	One of the following must be chosen: Thermalablation Cryoablation Electrochemotherapy Arterial Embolization Phenol Bisphosphonates Combination Other (free text box will be shown)
Complication (click 'Add Complication' to register)	
Complication date	Date of complication (YYYY-MM-DD).
Type	One of the following must be chosen: Wound infection only Deep infection Stroke Nerve injury Myocardial infarction Pulmonary embolism Pneumonia Respiratory failure DVT Other (free text box will be shown)
PATHFx	
Press 'Calculate PATHFx' to register data based on PATHFx variables (marked in purple) *	
Probability of survival 1 month	Will automatically be set from the performed calculation.
Probability of survival 3 month	Will automatically be set from the performed calculation.
Probability of survival 6 month	Will automatically be set from the performed calculation.
Probability of survival 12 month	Will automatically be set from the performed calculation.
Probability of survival 18 month	Will automatically be set from the performed calculation.
Probability of survival 24 month	Will automatically be set from the performed calculation.
Comment	Add an optional comment on the calculation.

* After pressing 'Calculate PATHFx' a summary of the registered variables is shown. Here you have a last opportunity to change anything (press 'Cancel') or proceed with the calculation (press 'OK').

Proceed with the calculation? ×

Is it ok to proceed with the calculation based on the following values?

Variable	Value
Gender	male
ECOG status	<=2
Primary tumor	female genital organs
Bone metastases	solitary
Visceral metastases	no
Complete bone fracture	no
Lymph node metastases	no
Hemoglobin	8.7
ALC	1
Surgeon estimate of survival	12

Figure 10 Example of the summary of registered data for the PATHFx variables, from the 'Surgery' tab

4.4 Radiotherapy

If radiotherapy has been performed, this is where you register that information for each relevant metastasis location already registered in [section 4.2](#).

Press 'Add Radiotherapy' to start registering (multiple entries can be added).

Variable	Information
Physician	Name of the physician responsible for the radiotherapy.
Radiotherapy date	Date of radiotherapy treatment (YYYY-MM-DD).
Metastasis location link	Choose the relevant metastasis location where radiotherapy has been performed (if this list is empty no location has yet been registered. See section 4.2)
Age at radiotherapy	Age at time of radiotherapy should be entered if not automatically generated.
Patient's BMI	The BMI (Body Mass Index) of the patient.
Metastases at the time of radiotherapy	Click 'Add Metastases' to add types of metastases. Skeletal is always selected. The following can also be chosen: Brain Liver Lung Lymph node Skeletal Other (free text box will be shown)

Variable	Information
	Unknown
Number of skeletal metastases	Number of skeletal metastases. One of the following must be chosen: Multiple Solitary Unknown
Physicians estimation of survival pre-radiotherapy (number of months)	Estimation of survival (in months)
Lab Data (click 'Add Lab Data' to register)	
Date	Date for laboratory testing (YYYY-MM-DD).
ALB	Preoperative Albumin (ALB) in g/L, within one week before the procedure; typical range (~34-45). For USA centers in which g/dL is used, multiply by 10 to convert to g/L. For instance, an ALB value of 4 g/dL = 40 g/L
ALP	Preoperative Alkaline Phosphatase (ALP) in U/L, one week before surgery. Typical range (~50-500)
CRP	Preoperative C-Reactive Protein (CRP) in mg/L, one week before surgery. Typical range (~0-100)
ESR	Preoperative Erythrocyte Sedimentation Rate (ESR) in mm/hour, one week before surgery. Typical range (~0-50)
HB	Preoperative Hemoglobin (HB) in g/L, one week before surgery. Typical range (~50-180). For USA centers in which g/dL is used, multiply by 10 to convert to g/L. For instance, a HB Value of 10 g/dL = 100 g/L
ALC	Preoperative Absolute Lymphocyte Count in 10 ⁹ cells / L, which is equivalent to other units commonly used in the USA such as K/mm ³ or K/ μ L, within one week before the procedure; typical range (~0-9)
Promis (click 'Add Promis' to register)	
Date for Promis	Date of Promis survey (YYYY-MM-DD).
Type	Type of Promis. One of the following must be chosen: Preop One month postop (+- 7 days) Six months postop (+- 14 days) 12 months postop (+- 30 days)
Mobility	Mobility score
Physical Function	Physical function score
Upper Extremity	Upper extremity score
Pain Behavior	Pain behavior score
Pain Inference	Pain inference score
Performance Status (click 'Add Performance Status' to register)	
Date of status	Date of performance status (YYYY-MM-DD).
ECOG status	Status per ECOG. One of the following must be chosen: 0 Fully active, able to carry on all pre-disease performance without restriction 1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature 2 Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours

Variable	Information
	3 Capable of only limited selfcare, confined to bed or chair more than 50 % of waking hours 4 Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair. 5 Dead
Karnofsky Status	Status per Karnofsky. One of the following must be chosen: 100 Normal, no complaints 90 Able to carry on normal activities. Minor signs or symptoms of disease 80 Normal activity with effort 70 Care for self. Unable to carry on normal activity or to do active work 60 Requires occasional assistance, but able to care for most of their needs 50 Requires considerable assistance and frequent medical care 40 Disabled. Requires special care and assistance 30 Severely disabled. Hospitalisation indicated thought death non-imminent 20 Very sick. Hospitalisation necessary. Active supportive treatment necessary 10 Moribund 0 Dead
Radiotherapy	
Pre-op radiotherapy	One of the following must be chosen: No Yes Unknown
Pre-op radiotherapy date - Start date	(YYYY-MM-DD).
Pre-op radiotherapy date - Stop date	(YYYY-MM-DD).
Total dose (gray)	
Number of fractions	
Post op radiotherapy	One of the following must be chosen: No Yes Unknown
Post-op radiotherapy date - Start date	(YYYY-MM-DD).
Post-op radiotherapy date - Stop date	(YYYY-MM-DD).
Surgery link	Choose a previously registered surgery to link to the post op radiotherapy (if this list is empty no surgery has yet been registered. See section 4.3)
Total dose (gray)	
Number of fractions	
Radiotherapy alone	One of the following must be chosen: No Yes Unknown
Main indication	Main indication for radiotherapy. One of the following must be chosen: Complete fracture, non-spinal Impending fracture, non-spinal

Variable	Information
	Complete fracture, neurological compromise Impending fracture, neurological compromise Complete fracture, other reason (free text box will be shown) Impending fracture, other reason (free text box will be shown)
Radiotherapy date - Start date	(YYYY-MM-DD).
Radiotherapy date - Stop date	(YYYY-MM-DD).
Total dose (gray)	
Number of fractions	
PATHFx (only visible for 'Radiotherapy Alone')	
Press 'Calculate PATHFx' to register data based on PATHFx variables (marked in purple) *	
Probability of survival 1 month	Will automatically be set from the performed calculation.
Probability of survival 3 month	Will automatically be set from the performed calculation.
Probability of survival 6 month	Will automatically be set from the performed calculation.
Probability of survival 12 month	Will automatically be set from the performed calculation.
Probability of survival 18 month	Will automatically be set from the performed calculation.
Probability of survival 24 month	Will automatically be set from the performed calculation.
Comment	Add an optional comment on the calculation.

* After pressing 'Calculate PATHFx' a summary of the registered variables is shown. Here you have a last opportunity to change anything (press 'Cancel') or proceed with the calculation (press 'OK').

4.5 PATHFx

Here you will see a summary for all the completed PATHFx calculations.

PATHFx Calculations

	1 month	3 months	6 months	12 months	18 months	24 months	Calculation date	Comment
Surgery - 2021-10-01	95%	84%	66%	58%	59%	54%	2022-11-23	

Figure 11 Example of PATHFx summary

4.6 Comments

Press 'Add Comment' to register comments (multiple entries can be added).

Variable	Information
Comment date	Date of comment (YYYY-MM-DD).
Commented by	Person making the comment
Comment	Comment