

Bone Metastasis Registry
Manual

Table of contents

1	The form	3
1.1	Primary data.....	3
1.2	Metastases locations	4
1.3	Surgery	5
1.4	Radiotherapy.....	10
1.5	PATHFx	13
1.6	Comments	13

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1 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 1 Example of patient information

1.1 Primary data

Variable	Information
Primary tumor	One of the following must be chosen: 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)	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: Lung: Non-small cell Small cell Unknown

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

1.2 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.

1.3 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

Surgery - 2020-05-05

Date of reoperation

2020-06-05

Close
Add reoperation

Figure 2 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/μL, 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
	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 though death non-imminent 20 Very sick. Hospitalisation necessary. Active supportive treatment necessary 10 Moribund 0 Dead
	Surgery
Main indication	Main indication for surgery. One of the following must be chosen: Complete fracture, non-spinal Impending fracture, non-spinal 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)
Operation Method	One of the following must be chosen: Hemi prosthesis Prosthesis, total joint replacement Prosthesis & acetabular reconstruct Mega/tumor prosthesis Glide screw plate Plate Recon nail (cervical screw) Intramedullary nail Laminectomy & posterior stabilization Laminectomy & anterior stabilization Laminectomy without stabilization Closed prosthetic reduction (only valid for Reoperation) Other (free text box will be shown)
Reason	The reason for the reoperation. Only valid for reoperation. One of the following must be chosen: Non-union Local tumor progression Stress fracture of bone Poor initial fixation (within 6 wks) Implant failure Technical error Prosthetic dislocation Wound infection Deep infection Other (free text box will be shown)
Operation strategy	One of the following must be chosen:

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

Cancel

Ok

Figure 3 Example of the summary of registered data for the PATHFx variables, from the 'Surgery' tab

1.4 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/μL, 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').

1.5 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 4 Example of PATHFx summary

1.6 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