|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| A  Systen Ids - Please do not change | F  Recommendation  Title | G  Recommendation as from PCFU (English) | H  Care Plan PCFU | I  Individualized decision (suggestion) SCP Care Plan PCFU |
| passport\_n.GUIDELINE\_T1.GUIDELINE\_T1 | Subsequent thyroid cancer | Counselling regarding the increased risk for developing differentiated thyroid to inform their HCP if they detect a thyroid mass (independent of the presence or absence of associated symptoms), every 5 years - Physical examination of the neck as part of a complete physical examination, whenever a survivor is assessed by a HCP - Counselling regarding options for differentiated thyroid carcinoma surveillance, at least every 5 years If the decision to commence surveillance is made, make a shared decision for one of these two surveillance modalities: - Neck palpation, every 1-2 years, starting 5 years after radiotherapy, or - Thyroid ultrasonographyw, every 3-5 years, starting 5 years after radiotherapy | A neck palpation every 1-2 years. An ultrasound of your thyroid gland every 3-5 years. | Neck palpation 1x/1-2 years OR - Thyroid ultrasound 1x/3-5 years  Note: start surveillance 5 years after exposure |
| passport\_n.GUIDELINE\_T2.GUIDELINE\_T2 | Subsequent breast cancer | Mammography and breast MRI every year if ≥ 25 years of age or ≥ 8 years from radiation, whichever occurs last | A mammography and a breast MRI every year | Mammography 1x/year  Breast MRI 1x year  Note: start at age ≥ 25 years or ≥ 8 years from radiation, whichever occurs last |
| assport\_n.GUIDELINE\_T3 .GUIDELINE\_T3 | Cardiac problems (High risk)  Cardiomyopathy and/or  Valvular disease and/or  Cardiac ischemia | A physical cardiac examination at every LTFU visit, at least every 5 years. Screening for modifiable cardiovascular risk factors (hypertension, diabetes, dyslipidaemia, obesity, smoking and low levels of physical activity).  - ECG once at entry into LTFU. Repeat ECG once after the age of 18 years if entry into LTFU was at a younger age. - Echocardiogram with specific attention to left ventricular systolic function, to valvular structure and function and to the pericardium, starting 2 years after treatment and at least every 2-3 years; Echocardiogram with specific attention to left ventricular function, prior to pregnancy or in the first trimester, if female  - Refer to a cardiologist if an abnormal ejection fraction or if other abnormalities are identified - Refer for interventions to help avert the risk of symptomatic cardiomyopathy if modifiable cardiovascular risk factors are identified Refer to a cardiologist if an abnormal ejection fraction or if other abnormalities are identified - Refer for interventions to help avert the risk of symptomatic cardiomyopathy if modifiable cardiovascular risk factors are identified | An ECG once and an echo of your heart at least every 2-3 years [and prior to attempting pregnancy or in the first trimester] | ECG 1x at entry LTFU - Echo heart: left ventricular systolic function at least 1x/2-3 years  - Echo heart: left ventricular systolic function prior to pregnancy or in the first trimester (if female)  Note: start echo 2 years after exposure. |
| passport\_n.GUIDELINE\_T46 .GUIDELINE\_T46 | Cardiac problems (standard risk)  Cardiomyopathy and/or  Valvular disease and/or  Cardiac ischemia | A physical cardiac examination at every LTFU visit, at least every 5 years. Screening for modifiable cardiovascular risk factors (hypertension, diabetes, dyslipidaemia, obesity, smoking and low levels of physical activity).  ECG once at entry into LTFU. Repeat ECG once after the age of 18 years if entry into LTFU was at a younger age.  - Echocardiogram with specific attention to left ventricular systolic function, to valvular structure and function and to the pericardium, starting 2 years after treatment and at least every 5 years; -Echocardiogram with specific attention to left ventricular function, prior to pregnancy or in the first trimester, if female  - Refer to a cardiologist if an abnormal ejection fraction or if other abnormalities are identified - Refer for interventions to help avert the risk of symptomatic cardiomyopathy if modifiable cardiovascular risk factors are identified | An ECG once and an echo of your heart at least every 5 years [and prior to attempting pregnancy or in the first trimester] | ECG 1x at entry LTFU - Echo heart: left ventricular systolic function + pericardium + valvular structure and function at least 1x/5 years  - Echo heart: left ventricular systolic function prior to pregnancy or in the first trimester (if female)  Note: start echo 2 years after exposure. |
| passport\_n.GUIDELINE\_T31.GUIDELINE\_T31 | Arrhythmia | A cardiac history at every LTFU visit, at least every 5 years  A physical cardiac examination at every LTFU visit, at least every 5 years  - ECG once at entry into LTFU - Repeat ECG once after the age of 18 years if entry into LTFU was at a younger age | NO/ included in cardiac problems |  |
| passport\_n.GUIDELINE\_T4 .GUIDELINE\_T4 | Male fertility problems and sexual dysfunction Impaired fertility Impaired spermatogenesis | All survivors at risk: - Counseling regarding the risk of impaired spermatogenesis and its implications for future health and fertility at the request of the survivor after informed discussion or when paternity is desired in the forseeable future, at least every 5 years  Post-pubertal survivors at risk that desire assessment of potential for future fertility: - Semen analysis | Have discussed the possibility to test your semen and get to know your fertility status | Semen analysis (if desired) |
| passport\_n.GUIDELINE\_T5.GUIDELINE\_T5 | Male fertility problems and sexual dysfunction Testosterone deficiency | All survivors at risk: - Counseling regarding the risk of impaired testosterone deficiency and its implications for future health and fertility at the request of the survivor after informed discussion or when paternity is desired in the forseeable future, at least every 5 years  Pre- and peri-pubertal survivors at risk: - Growth (height) and pubertal development and progression (Tanner stage) at least every year, with increasing frequency as clinically indicated depending on growth and pubertal progress  Note: Regular growth and pubertal monitoring should be started by no later than 12 years (and no earlier than 10 years) of age.  Post-pubertal survivors at risk: - Early morning testosterone at clinically appropriate time intervals - LH in addition to (early morning) testosterone if clinical signs of hypogonadism, previous low or borderline testosterone concentrations, or if an early morning testosterone sample cannot be obtained, at least every 2-3 years | Monitoring of your growth and pubertal development at least every year in currently pre-pubertal and peri-pubertal male survivors.  Blood tests every […] years and have discussed the possibility to test your semen and get to know your fertility status in currently post-pubertal male survivors | Growth and Tanner stage at least 1x/year (more often if clinically indicated)  Semen analysis (if desire) - Early morning testosterone at clinically appropriate intervals  - LH 1x/2-3 years (if clinically indicated or early morning testosterone not possible) |
| passport\_n.GUIDELINE\_T6.GUIDELINE\_T6 | Male fertility problems and sexual dysfunction Physical sexual dysfunction | All survivors at risk: - Counseling regarding the risk of physical sexual dysfunction (including erectile and ejaculatory dysfunction), and its implications for future health and fertility at the request of the survivor after informed discussion or when paternity is desired in the forseeable future, at least every 5 years  Post-pubertal survivors at risk - Sexual history every 5 years | Not included (see impaired fertility) | Not included (see impaired fertility) |
| passport\_n.GUIDELINE\_T7 .GUIDELINE\_T7 | Premature ovarian insufficiency Impaired fertility Amenorrhea Premature menopause | All survivors at risk:  - Counselling regarding the risk of premature ovarian insufficiency and its implications for future fertility, at least every 5 years - Not recommended: measurement of AMH as primary surveillance modality Pre- and peri-pubertal survivors at risk: - Monitoring of growth (height) and pubertal development and progression (Tanner stage) at least every year, with increasing frequency as clinically indicated based on growth and pubertal progression - FSH and oestradiolt in case of failure to initiate or progress through puberty at least for girls ≥ 11 years of age, and for girls with primary amenorrhoea (16 years of age) Post-pubertal survivors at risk: - History and physical examination with specific attention to premature ovarian insufficiency symptoms (amenorrhoea, irregular cycles) every 5 years - FSH and oestradiolt,u in case of menstrual cycle dysfunction suggesting premature ovarian insufficiency, or if assessment of potential for future fertility is desired | Monitoring of your growth and pubertal development every year in currently pre-pubertal or peri-pubertal female survivors  Monitoring of related symptoms and your menstrual cycle every 5 years in currently post-pubertal female survivors | Growth and Tanner stage 1x/year (more often if clinically indicated) - FSH and oestradiol (if clinically indicated)  Menstrual cycle 1x/5 years - FSH and oestradiol (if clinically indicated) |
| passport\_n.GUIDELINE\_T8.GUIDELINE\_T8 | Ear problems Hearing loss  Tinnitus | Survivors < 6 years of age at risk: - Extensive testing by audiologist every year, to begin no later than the end of treatment  Survivors ≥ 6 years of age at risk - Pure tone conventional audiometry testing at 1000-8000 Hz - Additional testing with high frequency audiometry > 8000 Hz (whenever equipment is available), to begin no later than the end of treatment - every other year if 6-12 years of age - every 5 years for adolescents and young adults ≥ 12 years of age | not included under 12 Y  A hearing test every 5 years in survivors currently 12 years or older | Audiometry 1000-8000 Hz 1x/5 years  - Audiometry > 8000 Hz 1x/5 years (if available)  Note: initiate surveillance no later than end of treatment. |
| passport\_n.GUIDELINE\_T9.GUIDELINE\_T9 | Impaired glucose metabolism and diabetes melitus | - Fasting blood glucose with or without HbA1c at least every 5 years | A blood glucose test at least every 5 years | Fasting blood glucose with or without HbA1c at least 1x/5 years |
| passport\_n.GUIDELINE\_T10.GUIDELINE\_T10 | Dyslipidemia | - Fasting lipid profile starting no later than at the age of 40 years, and at least every 5 years subsequentlyq | A blood lipid profile at least every 5 years | Fasting lipid profile at least 1x/5 years |
| passport\_n.GUIDELINE\_T11.GUIDELINE\_T11 | Overweight and obesity | - Height, weight and BMI at least every 2 years and at every LTFU visit | A height and weight measurement at least every 2 years | Height, weight, BMI at least 1x/2 years |
| passport\_n.GUIDELINE\_T12.GUIDELINE\_T12 | Hypertension | - Blood pressure measurement at least every 2 years and at every LTFU visit | A blood pressure measurement at least every 2 years and at every long-term follow-up visit | Blood pressure at least 1x/2 years and at every LTFU visit |
| passport\_n.GUIDELINE\_T13.GUIDELINE\_T13 | Reduced bone mineral density | A history with specific attention to risk factors (poor vitamin D and/or calcium intake, minimal weight-bearing exercise, comorbidities) and symptoms (back pain, fractures) of reduced bone mineral density at least every 5 years - DXA scan once, if possible, and thereafter as clinically indicated  Note: It might be considered to postpone the DXA-scan in pre-pubertal and pubertal survivors.  Other advice to be given: - Recommend adequate calcium and vitamin D intake, and adequate physical activity according to guidelines for the general population | A DXA scan once | DXA scan 1x at entry LTFU |
| passport\_n.GUIDELINE\_T14.GUIDELINE\_T14 | Osteonecrosis  Avascular necrosis | - A history for symptoms of osteonecrosis at least every 5 years. Suspicion of osteonecrosis should always be followed by a timely referral to an orthopaedic surgeon | Not included |  |
| passport\_n.GUIDELINE\_T15 .GUIDELINE\_T15 | Hypothalamic-pituitary (HP) axis problems (High risk) Growth hormone deficiency (GHD) TSH deficiency (TSHD) LH/FSH deficiency (LH/FSHD) ACTH deficiency (ACTHD) | refer directly to (paediatric) endocrinologist or see in multidisciplinary team) |  |  |
| passport\_n.GUIDELINE\_T16 .GUIDELINE\_T16 | Hypothalamic-pituitary (HP) axis problems (Standard risk) Growth hormone deficiency (GHD) TSH deficiency (TSHD) LH/FSH deficiency (LH/FSHD) ACTH deficiency (ACTHD) | Pre-pubertal and peri-pubertal survivors at risk: - Relevant clinical history for HP axis problems - Physical examination for symptoms and signs suggestive of HP axis problems - Height velocity in relation to parental height  - Tanner stage (note: boys exposed to gonadotoxic therapy (e.g. alkylating agents and radiotherapy to the testes) may have testes small for pubertal stage while in puberty) every 6 months, starting 6-12 months after completion of radiotherapy or directly after hydrocephalus or CSF shunt occurrence - fT4, TSH, morning cortisol every year, starting 6-12 months completion of radiotherapy or directly after hydrocephalus or CSF shunt occurrence Post-pubertal survivors at risk: - Relevant clinical history for HP axis problems - Physical examination for symptoms and signs suggestive of HP axis problems - Evaluation of menstrual cycle (females) - fT4, TSH, morning cortisol, IGF-1 - Morning testosterone, or free testosterone if overweight, and LH (males) - Estradiol, FSH and LH (females) every year, starting 6-12 months from the end of radiotherapy or directly after hydrocephalus or CSF shunt occurrence  Note: an IGF-1 level even as high as 0 SDS does not rule out GHD. Note: continue surveillance at least 15 years from exposure. Continuation of surveillance should be a shared decision between survivor and HCP considering available health care resources. If surveillance is terminated, the survivor should be educated about possible signs and symptoms of HP axis problems. | Monitoring of your growth and pubertal development every 6 months and blood tests every year in currently pre-pubertal and peri-pubertal male and female survivors  Monitoring of your menstrual cycle and blood tests every year– in currently post-pubertal female survivors  Blood tests every year in currently post-pubertal male survivors | Height velocity, Tanner stage 1x/6 months -  - fT4, TSH, morning cortisol 1x/year  Note: initiate surveillance at ≥ 6 months after radiotherapy, even in the absence of symptoms. Continue up to 15 years after radiotherapy exposure. Afterwards, continuation of surveillance is a shared decision.  fT4, TSH, morning cortisol, IGF-1 1x/year   Note: initiate surveillance at ≥ 6 months after diagnosis, even in the absence of symptoms. Continue up to 15 years after diagnosis. Afterwards, continuation of surveillance is a shared decision.  fT4, TSH, morning cortisol, IGF-1 1x/year  Morning testosterone or free testosterone 1x/year (in overweight males)  Note: initiate surveillance at ≥ 6 months after radiotherapy, even in the absence of symptoms. Continue up to 15 years after radiotherapy exposure. Afterwards, continuation of surveillance is a shared decision |
| passport\_n.GUIDELINE\_T17.GUIDELINE\_T17 | Central precocious puberty (CPP) For girls with age below 8 years | Relevant clinical history for symptoms of central precocious puberty - Physical examination for signs of central precocious puberty - Height velocity in relation to parental height - Tanner stage every 6 starting 6-12 months after completion of radiotherapy or directly after hydrocephalus or CSF shunt occurrence  Note: Continue surveillance until the age of 8 years for girls  - Refer to a paediatric endocrinologist if there are clinical symptoms and signs suggestive for central precocious puberty, or if morning testosterone is abnormal - Counsel survivors with (a suspicion of) central precocious puberty on overall health as well as the risk for short stature associated with untreated central precocious puberty, and assist them with coordinating and obtaining an early referral when appropriate |  |  |
| passport\_n.GUIDELINE\_T18.GUIDELINE\_T18 | Central precocious puberty (CPP) For boys with age below 9 yearss | Relevant clinical history for symptoms of central precocious puberty - Physical examination for signs of central precocious puberty - Height velocity in relation to parental height - Tanner stage every 6 months, starting 6-12 months after completion of radiotherapy or directly after hydrocephalus or CSF shunt occurrence - Morning testosterone every year, starting 6-12 months after completion of radiotherapy or directly after hydrocephalus or CSF shunt occurrence Note: Continue surveillance until the age of 9 years for boys. Boys exposed to radiotherapy to the testes may have testes small for pubertal stage while in puberty. Instead, morning testosterone (before 10:00 AM) should be used as screening modality as testicular volume may be unreliable |  |  |
| passport\_n.GUIDELINE\_T19.GUIDELINE\_T19 | Thyroid function problems Hypothyroidism Hyperthyroidism | A history with specific attention to hypothyroidism and/or hyperthyroidism  - TSH and fT4 measurement  - every year in survivors ≤ 18 years of age - at least every 2-3 years in survivors > 18 years of age Female survivors at risk of hypothyroidism: - Discuss the importance of measuring TSH and fT4 prior to attempting pregnancy and periodically during pregnancy at least every 5 years - Measure TSH and fT4 prior to attempting pregnancy and periodically during pregnancy | Blood tests of your thyroid gland function [every year] [at least every 2-3 years] [, before attempting pregnancy and periodically during pregnancy] | TSH, fT4 1x/year ( if ≤ 18 years)- -TSH, fT4 1x/2-3 years (if > 18 years)  -TSH, fT4 prior to attempting pregnancy and periodically during pregnancy (if female) |
|
| passport\_n.GUIDELINE\_T20 .GUIDELINE\_T20 | Cerebrovascular problem  Carotid artery disease Cerebrovascular accidents Aneurysm Cavernomas | Discuss the importance of controlling cardiovascular and stroke risk factors (hypertension, diabetes, dyslipidaemia, obesity, smoking and low levels of physical activity) - Perform imaging as appropriate and/or refer to a neurologist, neurosurgeon or vascular specialist | Not included |  |
| passport\_n.GUIDELINE\_T21 .GUIDELINE\_T21 | Neurocognitive problems Academic and school performance Attention Executive functions Intelligence Language Memory Processing speed Visual-motor integration Risk especially if the survivor was treated at a young age | A history with specific attention to educational and/or vocational progress or decline  - at least every 2 years in survivors ≤ 18 years of age - at least every 5 years in survivors > 18 years of age  - Refer to a (neuro)psychologist for a formal neuropsychological evaluation in case of abnormalities | Not included |  |
| passport\_n.GUIDELINE\_T22.GUIDELINE\_T22 | Peripheral neuropathy Sensory peripheral neuropathy Motor peripheral neuropathy | Refer to the appropriate HCP - Consider medication for painful neuropathy | Not included |  |
| passport\_n.GUIDELINE\_T23 .GUIDELINE\_T23 | Cataract | A history with specific attention to symptoms of cataract at least every 5 years - Refer to an ophthalmologist or ocular specialist in case of abnormalities | Not included |  |
| passport\_n.GUIDELINE\_T24.GUIDELINE\_T24 | Eye problems Lacrimal duct atrophy (risk with radioiodine therapy) Xerophtalmia Keratitis Telangiectasias Retinopathy Optic chiasm neuropathy Chronic painful eye Maculopathy Papillopathy Visual field deficits Glaucoma | A history with specific attention to symptoms of problems of the eye and orbit at least every 5 years - A physical eye examination for external eye abnormalities at least every 5 years - Refer to an ophthalmologist or ocular specialist in case of abnormalities | Not included |  |
| passport\_n.GUIDELINE\_T25.GUIDELINE\_T25 | Craniofacial growth problems Craniofacial growth disturbance Orbital hypoplasia Psychological adjustment difficulties due to craniofacial growth problems | A physical examination for craniofacial growth problems at least every 5 years Refer to a reconstructive craniofacial surgeon if craniofacial growth problems are identified - Perform a psychosocial history with specific attention to adjustment difficulties and refer to a psychologist if clinically indicated | Not included |  |
| passport\_n.GUIDELINE\_T26.GUIDELINE\_T26 | Spine scoliosis and kyphosis Spine scoliosis Spine kyphosis | A physical examination of the spine every year until growth is completed; the surveillance frequency may be increased during puberty. - Perform imaging and/or refer to an orthopaedic surgeon or physical therapist as clinically indicated in case of abnormalities | Not included |  |
| passport\_n.GUIDELINE\_T27.GUIDELINE\_T27 | Lower urinary tract problems Hemorrhagic cystitis Bladder fibrosis Dysfunctional voiding Vesicoureteral reflux Neurogenic bladder  Hydronephrosis | A history with specific attention to urinary tract symptoms at least every 5 years. Perform a urinalysis including cytology and urine culture - Refer to a urologist if the urinalysis results are abnormal | Not included |  |
| passport\_n.GUIDELINE\_T28.GUIDELINE\_T28 | Obstetric problems  Miscarriage Premature birth Low birth weight | All female survivors at risk of reproductive age: - Discuss the risk of adverse obstetric outcomes (miscarriage, premature birth, low birth weight; but not congenital anomalies) - High-risk obstetric surveillance during pregnancy | Not included |  |
| passport\_n.GUIDELINE\_T29.GUIDELINE\_T29 | Dental and oral problems Dental caries Dental developmental problems (especially if treated at a young age or having experienced a poor nutritional condition) Xerostomia Periodontal disease | Refer to specialist dental care or orthodontist if there are significant dental problems related to previous treatment | Not included |  |
| passport\_n.GUIDELINE\_T30.GUIDELINE\_T30 | Gastro-intestinal problems Bowel stenosis or obstruction Cholelithiasis Chronic enterocolitis Faecal incontinence Gastro-intestinal fistula Malabsorption Oesophageal stenosis or sticture Neurogenic bowel | Perform appropriate diagnostic tests and/or Refer to A surgeon or gastro-enterologist | Not included |  |
| passport\_n.GUIDELINE\_T32 .GUIDELINE\_T32 | Pulmonary problems Pulmonary dysfunction | History with specific attention to pulmonary dysfunction at least every 5 years - Physical pulmonary examination at least every 5 years - Pulmonary function tests, including spirometry and diffusing capacity for carbon monoxide (DLCO), once at entry into LTFU  - Consider pneumococcal vaccination status according to local or national guidelines  Other advice: - Avoid tobacco, quit smoking and/or reduce exposure to environmental smoke If initial pulmonary function test is abnormal: - Consult with or refer to pulmonologist  If any abnormalities are identified during subsequent follow-up visits - Repeat pulmonary function tests - Consult with or refer to pulmonologist if they are abnormal | Lung tests once, get a yearly influenza vaccination and avoid smoking - Pulmonary function tests including spirometry and DLCO 1x at entry LTFU - Influenza vaccination 1x/year - Check pneumococcal vaccination status according to local or national guidelines |  |
| passport\_n.GUIDELINE\_T33.GUIDELINE\_T33 | Renal problems Glomerular dysfunction Tubular dysfunction | Glomerular function testing including blood testing (creatinine), urine testing (creatinine, proteinuria), eGFR calculation, at least every 5 years - Additional tubular function testing including blood testing (Na, K, Mg, P, Ca, phosphate, albumin) and urine testing (glucose, phosphate) at least every 5 years Other advice: - Education about caution in the use of NSAIDs - Counselling about single kidney-related health risks - Electrolyte supplementation as guided by serum biochemistry if an electrolyte imbalance is detected - Refer to nephrologist if proteinuria and/or chronic kidney disease are identified | Blood and urine tests of the kidney at least every 5 years: | - Urine creatinine, proteinuria, glucose, P at least 1x/5 years - eGFR at least 1x/5 years |
| passport\_n.GUIDELINE\_T47.GUIDELINE\_T47 | Renal problems Tubular dysfunction | Glomerular function testing including blood testing (creatinine), urine testing (creatinine, proteinuria), eGFR calculation, at least every 5 years | Blood and urine tests of the kidney at least every 5 years | - Blood creatinine at least 1x/5 years - Urine creatinine, proteinuria at least 1x/5 years - eGFR at least 1x/5 years |
| passport\_n.GUIDELINE\_T34 .GUIDELINE\_T34 | Liver problems  Liver fibrosis or cirrhosis Hepatocellular liver injury  Hepatobiliary dysfunction  Biliary tract injury  Liver synthetic dysfunction | Physical examination for height, weight, BMI and signs of liver disease or bile duct injury (i.e. hepatosplenomegaly, spider naevi or pruritus)  - Serum liver enzyme concentrations (ALT, AST, gGT, ALP) once at entry into LTFU - Physical examination for height, weight, BMI and signs of liver disease or bile duct injury (i.e. hepatosplenomegaly, spider naevi or pruritus)  - Serum liver enzyme concentrations (ALT, AST, gGT, ALP) once at entry into LTFU  In case of increased liver enzyme values: - Between 1-2 x ULN: repeat the test within 1 year. - > 2x ULN: repeat the test within 2 months. In case of persistent liver abnormalities (> ULN): - Refer to a hepatologist or gastroenterologist for further examination if there is no obvious explanation (alcohol, medication, obesity) - Avoid or prescribe with caution potentially hepatotoxic medications and supplements - Evaluate body mass index and discuss healthy weight goals, especially in those with evidence of metabolic syndrome - Consider immunization against hepatitis A and B if not already immune - Counsel about importance of measures to maintain liver health: Cautious use or avoidance of alcohol intake Maintain a healthy weight and lifestyle Precautions to reduce viral transmission to household and sexual contacts in survivors with chronic HBV/HCV infection | Blood tests of the liver once | ALT, AST, gGT, ALP 1x at entry LTFU.  In case of chronic viral hepatitis: - Follow-up by an appropriate specialist (e.g. hepatologist or infectious diseases specialist) according to the local or national hepatitis clinical practice guidelines. |
|
| passport\_n.GUIDELINE\_T35 .GUIDELINE\_T35 | Iron overload | Serum ferritin, once at entry into LTFU In case of increased serum ferritin (>500 ng/ml): - Repeat test within 6 months  If persistent abnormal serum ferritin levels (>500 ng/ml): - Perform a MRI T2\* to quantify the liver iron content  If confirmed elevated liver iron content: - Refer to a hematologist or other specialist to start treatment, such as phlebotomy or chelation therapy | Blood tests of iron levels once | - Serum ferritin 1x at entry LTFU |
| passport\_n.GUIDELINE\_T36 .GUIDELINE\_T36 | Spleen problems | Educate about events that necessitate immediate start of therapeutic antibiotics and prompt evaluation by a HCPb - Ensure that therapeutic antibiotics are readily available - Advise wearing medical bracelet or carrying patient card - Discuss importance of seeking expert advice when travelling to endemic areas. In case of fever > 38.3 °C, infective or septic symptoms, or animal or human bite with skin break: - Arrange prompt evaluation by a HCP including a physical examination, blood count and blood culture - Immediately treat with therapeutic antibiotics according to local and national policies until blood culture results are available | Access to immediate medical help when you: • have a fever of > 38.3 °C (even if you do not have any other symptoms) • feel ill • have been bitten by a person or animal with skin break.  You might need antibiotics very soon after any of these events.  If you consider travelling to areas where malaria or other infectious diseases are endemic, it is recommended to seek advice from experts at the long-term follow-up clinic or at the travel clinic. They can advise you on the travel vaccines and anti-malarial medications that you might need. | Counsel about spleen-related risks and precautions  - Perform a blood count, blood culture and immediately treat with therapeutic antibiotics until blood culture results are available, in case of fever > 38.3 °C, illness or a bite mark with skin break |
| passport\_n.GUIDELINE\_T37.GUIDELINE\_T37 | Tumor predisposition | Surveillance strategy in survivors with, or with a suspicion of, a hereditary cancer syndromem: - Additional consultation by a clinical geneticist to determine individualised surveillance methods and frequency at entry into LTFU | Not included |  |
| passport\_n.GUIDELINE\_T38.GUIDELINE\_T38 | Subsequent melanoma and non-melanoma skin cancer Basal cell carcinoma Squamous cell carcinoma Melanoma | Self-examination for new spots and changing moles, at least every 6 months - History at least every 2 years - Skin examination at least every 2 years - Refer to a dermatologist in case of abnormalities | Not included |  |
| passport\_n.GUIDELINE\_T39.GUIDELINE\_T39 | Subsequent colorectal cancer | FOBT every 3 years  - As an alternative surveillance method, colonoscopy might be considered every 5 years  starting 5 years after radiation or at the age of 30 years, whichever occurs last - Positive FOBT should always be followed by a timely colonoscopy | [A stool sample test for hidden blood (FOBT) every 3 years] [a colonoscopy every 5 years] | FOBT 1x/3 years OR - Colonoscopy 1x/5 years  Note: start 5 years after radiation or at the age of 30 years, whichever occurs last |
| passport\_n.GUIDELINE\_T40.GUIDELINE\_T40 | Subsequent Oral Cancer | Discuss the importance of prompt reporting of new symptoms or masses - Discuss healthy lifestyle ecommendations - Encourage reduction of risk behaviour (smoking, alcohol consumption, drug use, sun exposure) - Encourage HPV vaccination (according to national guidelines) and consider advising safe sexual practices - Encourage participation in the national cancer screening programmes, unless more intensive or earlier surveillance is specified in the guidelinesl Surveillance strategy in all survivors: - Family history of malignancies, at least every 5 years. In survivors with, or with a suspicion of, a hereditary cancer syndromem: - Additional consultation by a clinical geneticist to determine individualised surveillance methods and frequency at entry into LTFU | Not included |  |
| passport\_n.GUIDELINE\_T42.GUIDELINE\_T42 | Subsequent bladder cancer | General advice: - Discuss the importance of prompt reporting of new symptoms or masses - Discuss healthy lifestyle recommendations - Encourage reduction of risk behaviour (smoking, alcohol consumption, drug use, sun exposure) - Encourage participation in the national cancer screening programmes, unless more intensive or earlier surveillance is specified in the guidelinesl  Surveillance strategy in all survivors: - Family history of malignancies, at least every 5 years  Surveillance strategy in survivors with, or with a suspicion of, a hereditary cancer syndromem: - Additional consultation by a clinical geneticist to determine individualised surveillance methods and frequency at entry into LTFU | Not included |  |
| passport\_n.GUIDELINE\_T43.GUIDELINE\_T43 | Subsequent Bone Cancer | General advice: - Discuss the importance of prompt reporting of new symptoms or masses - Discuss healthy lifestyle recommendations - Encourage reduction of risk behaviour (smoking, alcohol consumption, drug use, sun exposure) - Encourage HPV vaccination (according to national guidelines) and consider advising safe sexual practices - Encourage participation in the national cancer screening programmes, unless more intensive or earlier surveillance is specified in the guidelinesl  Surveillance strategy in all survivors: - Family history of malignancies, at least every 5 years  Surveillance strategy in survivors with, or with a suspicion of, a hereditary cancer syndromem: - Additional consultation by a clinical geneticist to determine individualised surveillance methods and frequency at entry into LTFU | Not included |  |
| passport\_n.GUIDELINE\_T44.GUIDELINE\_T44 | Subsequent lung cancer | General advice: - Discuss the importance of prompt reporting of new symptoms or masses - Discuss healthy lifestyle recommendations - Encourage reduction of risk behaviour (smoking, alcohol consumption, drug use, sun exposure) - Encourage participation in the national cancer screening programmes, unless more intensive or earlier surveillance is specified in the guidelinesl Surveillance strategy in all survivors: - Family history of malignancies, at least every 5 years Surveillance strategy in survivors with, or with a suspicion of, a hereditary cancer syndromem: - Additional consultation by a clinical geneticist to determine individualised surveillance methods and frequency at entry into LTFU | Not included |  |
| passport\_n.GUIDELINE\_T45.GUIDELINE\_T45 | Subsequent CNS neoplasms  Meningiomas (High-grade) gliomas Other CNS neoplasms (Pituitary tumors, neurilemmoma/schwannoma, opticus glioma, craniopharyngioma, medulloblastoma, pineal tumors, pilocytic astrocytoma, choroid plexus tumors, ependymoma, supratentorial tumor, oligodendroglioma, ganglioglioma) | Inform about symptoms and sign that may be related to a subsequent CNS neoplasm - Neurologic history at every LTFU visit, which may be at 1-5 year intervals - Neurologic examination at every LTFU visit, which may be at 1-5 year intervals Note: No recommendation can be formulated for routine MRI surveillance for asymptomatic survivors. The decision to undertake MRI surveillance should be made by the CAYA cancer survivor and HCP after careful consideration of the potential harms and benefits of MRI surveillance. | Discussed the advantages and disadvantages of regular MRIs with your doctor | Discuss potential harms and benefits of MRI surveillance |