SCREENING INSTRUMENT TUMOUR PREDISPOSITION SYNDROMES IN CHILDHOOD CANCER PATIENTS

Part I: Childhood cancer syndrome checklist (CCSC)
Version may 2016

EXCLUSION CRITERIA
Already diagnosed with a syndrome known to be associated with the current observed malignancy. No/yes
* see table 1: syndromes and tumours/leukaemia’s (instruction form)

INCLUSION CRITERIA
Age 0-18 years Yes/No
Newly diagnosed tumour or leukaemia Yes/No
Signed informed consent by both parents/guardians Yes/No
Signed informed consent by patient Yes/No/Not applicable (<12years)
Date informed consent __________/________/________

NB. If the criteria are not met, participation in the study stops here. There is no need in entering data in the online database OpenClinica.

PATIENT CHARACTERISTICS

<table>
<thead>
<tr>
<th>Study number:</th>
<th>Month of birth:</th>
<th>Year of birth:</th>
<th>Sex:</th>
<th>Ethnic background:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td>m/f</td>
<td>o Dutch</td>
</tr>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td></td>
<td>o Turkish</td>
</tr>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td></td>
<td>o Moroccan</td>
</tr>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td></td>
<td>o Hindu</td>
</tr>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td></td>
<td>o Unknown</td>
</tr>
<tr>
<td></td>
<td>__ __ __</td>
<td>__ __ __</td>
<td></td>
<td>o Other, i.e._____________________________</td>
</tr>
</tbody>
</table>

Oncologic diagnosis: _______________________

Anatomic localisation: _______________________

Month of diagnosis: __ __ __
Year of diagnosis: __ __ __

Therapy started: yes/no
    If so;
        [ ] Chemotherapy
        [ ] Surgery
        [ ] Radiotherapy
        Specify: _______________________

Previously tumour/leukaemia: yes/no
(Both benign and malignant)
    If so;
    Specify: _______________________

Treatment: _______________________

Pregnancy
Term labour __________/________/________ weeks + days
Weight at birth ____________ gram
Complications: Yes/No
    If so, which? __________________________________________________________________________

Development
Motor:
    [ ] Normal
    [ ] Late

Cognition:
    [ ] Normal
    [ ] Late

Puberty:
    [ ] Normal
    [ ] Not applicable yet
    [ ] Early
    [ ] Late

Other medical history:
(hospital admissions, contacts medical specialist, congenital organ defects)
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
FAMILY HISTORY
NB. Half-siblings are counted as full siblings

Table 1. Ask for the following aspects

<table>
<thead>
<tr>
<th>Who?</th>
<th>Tumour/leukaemia + age of diagnosis</th>
<th>Morphological abnormalities/ Congenital anomalies</th>
<th>Learning- and developmental difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>We use the following nomenclature:</td>
<td>Both benign and malignant tumours (including cysts) + type (which tumour) + location (what body part) + age of diagnosis</td>
<td>Congenital anomalies which stand out in appearance, where a person is operated on, where someone receives treatment for, or is limited by. + type (which anomaly) + location (what body part)</td>
<td>Learning difficulties, developmental delay, intellectual disabilities or behavioural problems for which extra support is necessary. + type (which difficulty/delay/problem) + degree of support</td>
</tr>
<tr>
<td>M= mother (mater)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P= father (pater)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F= brother (frater)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S= sister (soror)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fs = son (filius)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fe = daughter (filia)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For example for a cousin who is the son of the brother of mother: FsFM</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2. Please use the items listed in Table 1 when filling in the following table.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Are parents related? No/Yes

sibings
Number of brothers: | | |
Number of sisters: | | |
Are there any particularities with the brothers or sisters? No/Yes
If so, please fill in table 2.

parents
Number of brothers of father: | | |
Number of sisters of father: | | |
Number of brothers of mother: | | |
Number of sisters of mothers: | | |
Are there any particularities with the father or mother? No/Yes
If so, please fill in table 2.

uncles & aunts
Are there any particularities with the uncles or aunts? No/Yes
If so, please fill in table 2.

cousins
Are there any particularities with the cousins? No/Yes
If so, please fill in table 2.

grandparents
Number of sibs grandfather: | | |
Number of sibs grandmother: | | |
Number of sibs grandfather: | | |
Number of sibs grandmother: | | |
Are there any particularities with the grandfathers and grandmothers and their siblings? No/Yes
If so, please fill in table 2.

Are there relatives of whom you don’t have general information about their health? No/Yes
If so, who are they?

Please, store this checklist carefully.
| PHYSICAL EXAMINATION | Date of examination: | __ | __ | __ | __ | __ | __ | __ | __ | __ | __ | __ |
| ANTHROPOMETRICS | Height: | __ | __ | __ | __ | cm | Weight: | __ | __ | __ | __ | __ | __ | __ | __ | kg | Head circumference: | __ | __ | __ | __ | cm |

Please use the booklet *Tumour Predisposition syndrome in Childhood Cancer Screening Instrument, part II: Definitions and pictures* when filling in this list. For items with a * there are illustrating pictures available.

**HEAD**
- **Cranium**
  - Scalp tumours: no/yes/unable to evaluate/not evaluated
  - Brittle hair*: no/yes/unable to evaluate/not evaluated

- **Eyes**
  - Cataract*: no/yes/unable to evaluate/not evaluated
  - Visible nerve fibres on cornea*: no/yes/unable to evaluate/not evaluated
  - Photosensitivity*: no/yes/unable to evaluate/not evaluated
    - If so:
      - [ ] eyes
      - [ ] skin

- **Ears**
  - Crease/pits of ear lobule*: no/yes/unable to evaluate/not evaluated
  - (Posterior) helical pits of ear helix*: no/yes/unable to evaluate/not evaluated

**Mouth/oral region**
- **Leukoplakia***: no/yes/unable to evaluate/not evaluated
- **Tongue***:
  - normal/abnormal/unable to evaluate/not evaluated
  - If abnormal:
    - [ ] large
    - [ ] lobulated
    - [ ] protruding

- **Oral pigmentation***: no/yes/unable to evaluate/not evaluated
- **Oral tumours**: no/yes/unable to evaluate/not evaluated
- **Abnormal oral mucosa (cobblestone)***: no/yes/unable to evaluate/not evaluated
- **Mucosal neurinomas***: no/yes/unable to evaluate/not evaluated
- **Papilloma peri-orificial***: no/yes/unable to evaluate/not evaluated

**THORAX**
- **Supernumerary nipples***: no/yes/unable to evaluate/not evaluated

**ABDOMEN**
- **Umbilical hernia***: no/yes/unable to evaluate/not evaluated

**EXTRIMITIES**
- **Asymmetry (length, width, both)**: no/yes/unable to evaluate/not evaluated
  - If so:
    - [ ] arms
    - [ ] legs
- **Palmar pits**: no/yes/unable to evaluate/not evaluated

**GENITALIA**
- **Abnormal genital pigmentation***: no/yes/unable to evaluate/not evaluated
- **Ambiguous genitalia***: no/yes/unable to evaluate/not evaluated

**SKIN**
- **Telangiectasia***: no/yes/unable to evaluate/not evaluated
  - If so:
    - [ ] conjunctival
    - [ ] nasal
    - [ ] oral
- **Tumours***: no/yes/unable to evaluate/not evaluated
- **Blue naevus***: no/yes/unable to evaluate/not evaluated
- **Axillary freckling***: no/yes/unable to evaluate/not evaluated
- **Hyperpigmentation***: no/yes/unable to evaluate/not evaluated
- **Thin skin/generalized skin atrophy***: no/yes/unable to evaluate/not evaluated

**NEUROLOGICAL**
- **Ataxia***: no/yes/unable to evaluate/not evaluated
  - If so:
    - [ ]
- **Cranial nerve palsy***: no/yes/unable to evaluate/not evaluated
  - If so:
    - [ ]

**ENDOCRINE**
- **Enlarged thyroid***: no/yes/unable to evaluate/not evaluated

Correctly completed and verified by: __ | __ | __ | __ | __ | ___ |