|  |
| --- |
| **Questionnaire on availability and accessibility of medicines for paediatric malignancies in Europe**PART I: antineoplastic agents  |

Top of Form



Thank you for taking the time to participate in this survey on the availability and accessibility of essential medicines for children and adolescents with cancer: Part I – antineoplastic agents.

Please note that the [online survey](https://www.surveymonkey.co.uk/r/L3R2Q35) set up requires completion in one sitting.

You can use the current text version to prepare your answers and fill them in online here: <https://www.surveymonkey.co.uk/r/L3R2Q35> **before 30 June 2018***.*

There are 20 questions in total. All questions marked with an asterisk (\*) are mandatory.

The list of medicines is provided directly in some of the questions and also provided as Annex should you require it during the response preparation.

*SIOPE thanks ESMO for allowing use of its survey questions and methodology from the ESMO studies on the availability of cancer medicines for solid adult tumours to serve as a basis for the development of SIOPE’s survey on the availability of cancer medicines for paediatric malignancies.*

**\***1. **Are the following medicines approved for use in the treatment of children in your country?**

Terminology: For the purposes of the survey, ‘approved’ means that the medicine has obtained an official Marketing Authorisation for use in children from the competent authority/ies in the country

|  | **Yes** | **No** | **Don’t know** |
| --- | --- | --- | --- |
| 13 cis retinoic acid |[ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ]
| Etoposide injection  |[ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ]
| Hydrocortisone injection |[ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ]
| Methylprednisolone oral tablet  |[ ] [ ] [ ]
| Methylprednisolone injection  |[ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ]
| Prednisone oral liquid  |[ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ]

**\*2. Are the following medicines used in the treatment of children in your country?**

Terminology: For the purposes of the survey, ‘used in children’ means that the medicine is used independently of its official indication, so including off-label use.

|  | **Yes** | **No** | **Don’t know** |
| --- | --- | --- | --- |
| 13 cis retinoic acid |[ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ]
| Etoposide injection |[ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ]
| Hydrocortisone injection  |[ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ]
| Methylprednisolone oral tablet  |[ ] [ ] [ ]
| Methylprednisolone injection  |[ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ]
| Prednisone oral liquid  |[ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ]

**\***3. **Are the following medicines available in your country?**

Terminology: For the purposes of the survey, ‘available’ means that the medicine can be obtained as needed and in a timely manner.

|  | **Always** | **Usually** | **Occasionally** | **Never** | **Don’t know** |
| --- | --- | --- | --- | --- | --- |
| 13 cis retinoic acid  |[ ] [ ] [ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ] [ ] [ ]
| Etoposide injection |[ ] [ ] [ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ] [ ] [ ]
| Hydrocortisone injection |[ ] [ ] [ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ] [ ] [ ]
| Methylprednisolone oral tablet |[ ] [ ] [ ] [ ] [ ]
| Methylprednisolone injection  |[ ] [ ] [ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ] [ ] [ ]
| Prednisone oral liquid  |[ ] [ ] [ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ] [ ] [ ]

#### 4. \*If i****n the previous question you answered ‘Never’ for the below listed medicines, please define the reasons for non-availability over the past 24 months:****

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Not licensed in the country** | **Not procured in the country** | **Budget limitations** | **Don’t know** | **Other\*** |
| [in this table you will see the medicines that were selected as ‘Never’] |[ ] [ ] [ ] [ ] [ ]

#### 5. \*Other (please specify the reasons for non-availability over the past 24 months)

|  |  |
| --- | --- |
| [in this table you will see the medicines that were selected as ‘Other\*’] |  |

#### 6. \*If in ****question 3 you answered ‘Usually’ or ‘Occasionally’ for the below listed medicines, please define the reasons for intermittent non-availability over the past 24 months:****

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Shortages | Budget limitations | Don’t know | Other\* |
| [in this table you will see the medicines that were selected as ‘Usually’ or ‘Occasionally’ ] |[ ] [ ] [ ] [ ]

7. **\*Other (please specify the reasons for intermittent non-availability over the past 24 months)**

|  |  |  |
| --- | --- | --- |
| [in this table you will see the medicines that were selected as ‘Other\*’] |  |  |

#### 8. \*If ****you indicated experiencing Shortages of medicines in your country, please indicate which options, if any, were available to overcome them:****

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Using substitutes** | **Borrowing from other countries** | **Using another protocol** | **Postponing therapy** | **Obtaining funding/support from NGOs** | **Not able to overcome shortages** | **Don’t know** | **Other\*** |
| [in this table you will see the medicines that were selected as ‘Shortages’] | [ ]  |[ ] [ ] [ ] [ ] [ ] [ ] [ ]

#### 9. \*Other (please specify how did you overcome shortages)

|  |  |
| --- | --- |
| [in this table you will see the medicines that were selected as ‘Other\*’] |  |

#### \*10. ****Did you face issues prescribing the following medicines to children in your country in the past 24 months?****

|  | **Yes** | **No** | **Not applicable** |
| --- | --- | --- | --- |
| 13 cis retinoic acid |[ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ]
| Etoposide injection  |[ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ]
| Hydrocortisone injection  |[ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea  |[ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ]
| Methylprednisolone oral tablet  |[ ] [ ] [ ]
| Methylprednisolone injection  |[ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ]
| Prednisone oral liquid |[ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ]

#### \*11. (If) ****In the previous question you answered ‘Yes’ for the below listed medicines, how were these barriers to prescribing overcome in your country?****

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Obtaining special authorisation from national medicines agency** | **Obtaining special authorisation from manufacturer** | **Obtaining special authorisation from wholesaler** | **Obtaining insurance pre-approval per patient** | **Don’t know** | **Other\*** |
| [in this table you will see the medicines that were selected as ‘Yes’] |[ ] [ ] [ ] [ ] [ ] [ ]

#### 12. \*Other (please specify how were these barriers to prescribing overcome in your country

|  |  |
| --- | --- |
| [in this table you will see the medicines that were selected as ‘Other\*’] |  |

#### \*13. ****Do patients/parents have to incur out-of-pocket costs for the following medicines?****

|  | **Yes** | **No** | **Don’t know** |
| --- | --- | --- | --- |
| 13 cis retinoic acid |[ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ]
| All-trans retinoic acid  |[ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ]
| Dexamethasone tablet |[ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ]
| Etoposide injection  |[ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ]
| Hydrocortisone injection  |[ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ]
| Melphalan tablet |[ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ]
| Methylprednisolone oral tablet  |[ ] [ ] [ ]
| Methylprednisolone injection  |[ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ]
| Prednisone oral liquid |[ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ]

#### \*14. (If) ****In the previous question you answered Yes for the below listed medicines, please select which proportion of out of pocket costs applies, approximately?****

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **25% of cost** | **50% of cost** | **Full cost** | **Don’t know** | **Other\*** |
| [in this table you will see the medicines that were selected as ‘Yes’] |[ ] [ ] [ ] [ ] [ ]

#### 15. \*Other (please specify which proportion of out-of-pocket costs applies)

|  |  |
| --- | --- |
| [in this table you will see the medicines that were selected as ‘Other\*’] |  |

#### \*16. ****Are the following orally administrable medicines available in child-friendly formulations and doses?****

|  | **Always** | **Usually** | **Occasionally** | **Never** | **Don’t know** | **Not applicable** |
| --- | --- | --- | --- | --- | --- | --- |
| 13 cis retinoic acid |[ ] [ ] [ ] [ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ] [ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ] [ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ] [ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ] [ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ] [ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ] [ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ] [ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ] [ ] [ ] [ ]
| Methylprednisolone oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ] [ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ] [ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ] [ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ] [ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ] [ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ] [ ] [ ] [ ]
| Prednisone oral liquid  |[ ] [ ] [ ] [ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ] [ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ] [ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ] [ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]

#### \*17. ****When medicines are not available in a child-friendly dose or formulation, what alternatives are available (in general/across agents covered)?****

[ ]  Preparation on the hospital ward by nurses

[ ]  Centralised preparation by hospital pharmacy only for in-patients

[ ]  Centralised preparation by hospital pharmacy for both in- and out- patients

[ ]  Preparation by any other pharmacy as additional service

[ ]  Don't know

[ ]  Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

#### \*18.  ****Would you like your participation in the survey to be acknowledged?****

[ ]  Yes

[ ]  No

#### 19. ****If your answer is yes, please complete the below:****

First name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Last name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

#### \*20.  ****Country****

#### \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Annex: Reference list of anti-neoplastic medicines considered in the survey

|  |
| --- |
| 13 cis retinoic acid |[ ] [ ] [ ] [ ] [ ] [ ]
| 5-fluorouracil |[ ] [ ] [ ] [ ] [ ] [ ]
| All-trans retinoic acid |[ ] [ ] [ ] [ ] [ ] [ ]
| Asparaginase Erwinia |[ ] [ ] [ ] [ ] [ ] [ ]
| Asparaginase (escherichia coli) |[ ] [ ] [ ] [ ] [ ] [ ]
| Asparaginase (PEG-asparaginase) |[ ] [ ] [ ] [ ] [ ] [ ]
| Bleomycin |[ ] [ ] [ ] [ ] [ ] [ ]
| Blinatumomab |[ ] [ ] [ ] [ ] [ ] [ ]
| Bortezomib |[ ] [ ] [ ] [ ] [ ] [ ]
| Busulfan injection  |[ ] [ ] [ ] [ ] [ ] [ ]
| Busulfan oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Carboplatin |[ ] [ ] [ ] [ ] [ ] [ ]
| Cisplatin |[ ] [ ] [ ] [ ] [ ] [ ]
| Clofarabine |[ ] [ ] [ ] [ ] [ ] [ ]
| Crizotinib oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Cyclophosphamide |[ ] [ ] [ ] [ ] [ ] [ ]
| Cytarabine |[ ] [ ] [ ] [ ] [ ] [ ]
| Cytarabine liposomal (DepoCyte) |[ ] [ ] [ ] [ ] [ ] [ ]
| Dacarbazine |[ ] [ ] [ ] [ ] [ ] [ ]
| Dactinomycin |[ ] [ ] [ ] [ ] [ ] [ ]
| Daunorubicin |[ ] [ ] [ ] [ ] [ ] [ ]
| Daunorubicin liposomal |[ ] [ ] [ ] [ ] [ ] [ ]
| Dexamethasone injection |[ ] [ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral liquid |[ ] [ ] [ ] [ ] [ ] [ ]
| Dexamethasone oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Dinutuximab |[ ] [ ] [ ] [ ] [ ] [ ]
| Docetaxel |[ ] [ ] [ ] [ ] [ ] [ ]
| Doxorubicin |[ ] [ ] [ ] [ ] [ ] [ ]
| Epirubicine |[ ] [ ] [ ] [ ] [ ] [ ]
| Etoposide injection  |[ ] [ ] [ ] [ ] [ ] [ ]
| Etoposide phosphate |[ ] [ ] [ ] [ ] [ ] [ ]
| Etoposide oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Everollimus |[ ] [ ] [ ] [ ] [ ] [ ]
| Fludarabine |[ ] [ ] [ ] [ ] [ ] [ ]
| Gemcitabine |[ ] [ ] [ ] [ ] [ ] [ ]
| Hydrocortisone injection |[ ] [ ] [ ] [ ] [ ] [ ]
| Hydroxycarbamide/hydroxyurea |[ ] [ ] [ ] [ ] [ ] [ ]
| Idarubicine |[ ] [ ] [ ] [ ] [ ] [ ]
| Ifosfamide |[ ] [ ] [ ] [ ] [ ] [ ]
| Imatinib |[ ] [ ] [ ] [ ] [ ] [ ]
| Ipilimumab |[ ] [ ] [ ] [ ] [ ] [ ]
| Irinotecan |[ ] [ ] [ ] [ ] [ ] [ ]
| Lomustine oral tablet (CCNU) |[ ] [ ] [ ] [ ] [ ] [ ]
| Melphalan injection  |[ ] [ ] [ ] [ ] [ ] [ ]
| Melphalan oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Mercaptopurine |[ ] [ ] [ ] [ ] [ ] [ ]
| Methotrexate |[ ] [ ] [ ] [ ] [ ] [ ]
| Methylprednisolone oral tablet  |[ ] [ ] [ ] [ ] [ ] [ ]
| Methylprednisolone injection |[ ] [ ] [ ] [ ] [ ] [ ]
| Mitoxantrone |[ ] [ ] [ ] [ ] [ ] [ ]
| Oxaliplatin |[ ] [ ] [ ] [ ] [ ] [ ]
| Paclitaxel |[ ] [ ] [ ] [ ] [ ] [ ]
| Pamidronate |[ ] [ ] [ ] [ ] [ ] [ ]
| Peginterferon alfa 2b |[ ] [ ] [ ] [ ] [ ] [ ]
| Prednisone oral tablet  |[ ] [ ] [ ] [ ] [ ] [ ]
| Prednisone oral liquid  |[ ] [ ] [ ] [ ] [ ] [ ]
| Procarbazine |[ ] [ ] [ ] [ ] [ ] [ ]
| Rituximab  |[ ] [ ] [ ] [ ] [ ] [ ]
| Temozolomide  |[ ] [ ] [ ] [ ] [ ] [ ]
| Thiotepa |[ ] [ ] [ ] [ ] [ ] [ ]
| Tioguanine |[ ] [ ] [ ] [ ] [ ] [ ]
| Topotecan |[ ] [ ] [ ] [ ] [ ] [ ]
| Trofosfamide oral tablet |[ ] [ ] [ ] [ ] [ ] [ ]
| Vinblastine |[ ] [ ] [ ] [ ] [ ] [ ]
| Vincristine |[ ] [ ] [ ] [ ] [ ] [ ]
| Vindesine |[ ] [ ] [ ] [ ] [ ] [ ]
| Vinorelbine injection  |[ ] [ ] [ ] [ ] [ ] [ ]
| Zoledronate |[ ] [ ] [ ] [ ] [ ] [ ]