|  |
| --- |
| **Questionnaire on availability and accessibility of medicines for paediatric malignancies in Europe** |

PART II: Palliative, supportive and pain control medicines **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 II - palliative, supportive and pain control medicines.

Please note that the [online survey](https://www.surveymonkey.co.uk/r/78HYVQ8) 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/78HYVQ8> **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.*

**Bottom of Form**

**\*** 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** |
| --- | --- | --- | --- |
| Halothane |  |  |  |
| Isoflurane |  |  |  |
| Nitrous Oxide |  |  |  |
| Oxygen |  |  |  |
| Ketamine |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |
| D bupivacaine |  |  |  |
| D lidocaine |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |
| ephedrine |  |  |  |
| atropine |  |  |  |
| D midazolam |  |  |  |
| Acetylsalicytic acid |  |  |  |
| Ibubrofen |  |  |  |
| Paracetamol |  |  |  |
| Codeine |  |  |  |
| Fentanyl |  |  |  |
| Morphine |  |  |  |
| Methadone |  |  |  |
| Amitriptyne |  |  |  |
| Cyclizine |  |  |  |
| Diazepam |  |  |  |
| Docusate sodium |  |  |  |
| Fluoxetine |  |  |  |
| Haloperidol |  |  |  |
| Hyoscine butylbromide |  |  |  |
| Hyoscine hydrobromide |  |  |  |
| Lactulose |  |  |  |
| Loperamide |  |  |  |
| Metoclopramide |  |  |  |
| Midazolam |  |  |  |
| Ondansetron |  |  |  |
| Sen(n)a |  |  |  |
| Aciclovir |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |
| Allopurinol |  |  |  |
| Filgastrim or lenograstim |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |
| Mesna |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |
| Rasburicase |  |  |  |
| Corticosteroid (eye drop) |  |  |  |

**\*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** |
| --- | --- | --- | --- |
| Halothane |  |  |  |
| Isoflurane |  |  |  |
| Nitrous Oxide |  |  |  |
| Oxygen |  |  |  |
| Ketamine |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |
| D bupivacaine |  |  |  |
| D lidocaine |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |
| ephedrine |  |  |  |
| atropine |  |  |  |
| D midazolam |  |  |  |
| Acetylsalicytic acid |  |  |  |
| Ibubrofen |  |  |  |
| Paracetamol |  |  |  |
| Codeine |  |  |  |
| Fentanyl |  |  |  |
| Morphine |  |  |  |
| Methadone |  |  |  |
| Amitriptyne |  |  |  |
| Cyclizine |  |  |  |
| Diazepam |  |  |  |
| Docusate sodium |  |  |  |
| Fluoxetine |  |  |  |
| Haloperidol |  |  |  |
| Hyoscine butylbromide |  |  |  |
| Hyoscine hydrobromide |  |  |  |
| Lactulose |  |  |  |
| Loperamide |  |  |  |
| Metoclopramide |  |  |  |
| Midazolam |  |  |  |
| Ondansetron |  |  |  |
| Sen(n)a |  |  |  |
| Aciclovir |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |
| Allopurinol |  |  |  |
| Filgastrim or lenograstim |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |
| Mesna |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |
| Rasburicase |  |  |  |
| Corticosteroid (eye drop) |  |  |  |

**\***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** |
| --- | --- | --- | --- | --- | --- |
| Halothane |  |  |  |  |  |
| Isoflurane |  |  |  |  |  |
| Nitrous Oxide |  |  |  |  |  |
| Oxygen |  |  |  |  |  |
| Ketamine |  |  |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |  |  |
| D bupivacaine |  |  |  |  |  |
| D lidocaine |  |  |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |  |  |
| ephedrine |  |  |  |  |  |
| atropine |  |  |  |  |  |
| D midazolam |  |  |  |  |  |
| Acetylsalicytic acid |  |  |  |  |  |
| Ibubrofen |  |  |  |  |  |
| Paracetamol |  |  |  |  |  |
| Codeine |  |  |  |  |  |
| Fentanyl |  |  |  |  |  |
| Morphine |  |  |  |  |  |
| Methadone |  |  |  |  |  |
| Amitriptyne |  |  |  |  |  |
| Cyclizine |  |  |  |  |  |
| Diazepam |  |  |  |  |  |
| Docusate sodium |  |  |  |  |  |
| Fluoxetine |  |  |  |  |  |
| Haloperidol |  |  |  |  |  |
| Hyoscine butylbromide |  |  |  |  |  |
| Hyoscine hydrobromide |  |  |  |  |  |
| Lactulose |  |  |  |  |  |
| Loperamide |  |  |  |  |  |
| Metoclopramide |  |  |  |  |  |
| Midazolam |  |  |  |  |  |
| Ondansetron |  |  |  |  |  |
| Sen(n)a |  |  |  |  |  |
| Aciclovir |  |  |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |  |  |
| Allopurinol |  |  |  |  |  |
| Filgastrim or lenograstim |  |  |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |  |  |
| Mesna |  |  |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |  |  |
| Rasburicase |  |  |  |  |  |
| Corticosteroid (eye drop) |  |  |  |  |  |

#### 4. \*****If in 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. \*****Where 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** |
| --- | --- | --- | --- |
| Halothane |  |  |  |
| Isoflurane |  |  |  |
| Nitrous Oxide |  |  |  |
| Oxygen |  |  |  |
| Ketamine |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |
| D bupivacaine |  |  |  |
| D lidocaine |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |
| ephedrine |  |  |  |
| atropine |  |  |  |
| D midazolam |  |  |  |
| Acetylsalicytic acid |  |  |  |
| Ibubrofen |  |  |  |
| Paracetamol |  |  |  |
| Codeine |  |  |  |
| Fentanyl |  |  |  |
| Morphine |  |  |  |
| Methadone |  |  |  |
| Amitriptyne |  |  |  |
| Cyclizine |  |  |  |
| Diazepam |  |  |  |
| Docusate sodium |  |  |  |
| Fluoxetine |  |  |  |
| Haloperidol |  |  |  |
| Hyoscine butylbromide |  |  |  |
| Hyoscine hydrobromide |  |  |  |
| Lactulose |  |  |  |
| Loperamide |  |  |  |
| Metoclopramide |  |  |  |
| Midazolam |  |  |  |
| Ondansetron |  |  |  |
| Sen(n)a |  |  |  |
| Aciclovir |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |
| Allopurinol |  |  |  |
| Filgastrim or lenograstim |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |
| Mesna |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |
| Rasburicase |  |  |  |
| Corticosteroid (eye drop) |  |  |  |

#### 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** |
| --- | --- | --- | --- |
| Halothane |  |  |  |
| Isoflurane |  |  |  |
| Nitrous Oxide |  |  |  |
| Oxygen |  |  |  |
| Ketamine |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |
| D bupivacaine |  |  |  |
| D lidocaine |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |
| ephedrine |  |  |  |
| atropine |  |  |  |
| D midazolam |  |  |  |
| Acetylsalicytic acid |  |  |  |
| Ibubrofen |  |  |  |
| Paracetamol |  |  |  |
| Codeine |  |  |  |
| Fentanyl |  |  |  |
| Morphine |  |  |  |
| Methadone |  |  |  |
| Amitriptyne |  |  |  |
| Cyclizine |  |  |  |
| Diazepam |  |  |  |
| Docusate sodium |  |  |  |
| Fluoxetine |  |  |  |
| Haloperidol |  |  |  |
| Hyoscine butylbromide |  |  |  |
| Hyoscine hydrobromide |  |  |  |
| Lactulose |  |  |  |
| Loperamide |  |  |  |
| Metoclopramide |  |  |  |
| Midazolam |  |  |  |
| Ondansetron |  |  |  |
| Sen(n)a |  |  |  |
| Aciclovir |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |
| Allopurinol |  |  |  |
| Filgastrim or lenograstim |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |
| Mesna |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |
| Rasburicase |  |  |  |
| Corticosteroid (eye drop) |  |  |  |

#### 14. \*(If) i****n 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** |
| --- | --- | --- | --- | --- | --- | --- |
| D lidocaine |  |  |  |  |  |  |
| D midazolam |  |  |  |  |  |  |
| Acetylsalicytic acid |  |  |  |  |  |  |
| Ibubrofen |  |  |  |  |  |  |
| Paracetamol |  |  |  |  |  |  |
| Codeine |  |  |  |  |  |  |
| Fentanyl |  |  |  |  |  |  |
| Morphine |  |  |  |  |  |  |
| Methadone |  |  |  |  |  |  |
| Amitriptyne |  |  |  |  |  |  |
| Cyclizine |  |  |  |  |  |  |
| Diazepam |  |  |  |  |  |  |
| Docusate sodium |  |  |  |  |  |  |
| Fluoxetine |  |  |  |  |  |  |
| Haloperidol |  |  |  |  |  |  |
| Hyoscine hydrobromide |  |  |  |  |  |  |
| Lactulose |  |  |  |  |  |  |
| Loperamide |  |  |  |  |  |  |
| Metoclopramide |  |  |  |  |  |  |
| Midazolam |  |  |  |  |  |  |
| Ondansetron |  |  |  |  |  |  |
| Sen(n)a |  |  |  |  |  |  |
| Aciclovir |  |  |  |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |  |  |  |
| Allopurinol |  |  |  |  |  |  |
| Mesna |  |  |  |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |  |  |  |
| Corticosteroid (eye drop) |  |  |  |  |  |  |

#### \*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 palliative, supportive and pain control medicines considered in the survey

|  |  |  |  |
| --- | --- | --- | --- |
| Halothane |  |  |  |
| Isoflurane |  |  |  |
| Nitrous Oxide |  |  |  |
| Oxygen |  |  |  |
| Ketamine |  |  |  |
| Propofol (thiopental as alternative) |  |  |  |
| D bupivacaine |  |  |  |
| D lidocaine |  |  |  |
| lidocaine + epinephrine (adrenaline) |  |  |  |
| ephedrine |  |  |  |
| atropine |  |  |  |
| D midazolam |  |  |  |
| Acetylsalicytic acid |  |  |  |
| Ibubrofen |  |  |  |
| Paracetamol |  |  |  |
| Codeine |  |  |  |
| Fentanyl |  |  |  |
| Morphine |  |  |  |
| Methadone |  |  |  |
| Amitriptyne |  |  |  |
| Cyclizine |  |  |  |
| Diazepam |  |  |  |
| Docusate sodium |  |  |  |
| Fluoxetine |  |  |  |
| Haloperidol |  |  |  |
| Hyoscine butylbromide |  |  |  |
| Hyoscine hydrobromide |  |  |  |
| Lactulose |  |  |  |
| Loperamide |  |  |  |
| Metoclopramide |  |  |  |
| Midazolam |  |  |  |
| Ondansetron |  |  |  |
| Sen(n)a |  |  |  |
| Aciclovir |  |  |  |
| Ganciclovir (for CMV reactivation) |  |  |  |
| Clinically relevant broad spectrum IV antibiotics |  |  |  |
| Sulphametoxazol with trimethoprim, or equivalent IV therapy for pneumocystis jerovicii |  |  |  |
| Clinically relevant antifungal agent(s) for prophylaxis |  |  |  |
| Clinically relevant antifungal agent(s) for treatment of invasive fungal infections |  |  |  |
| Allopurinol |  |  |  |
| Filgastrim or lenograstim |  |  |  |
| Calcium folinate or calcium levofolinate |  |  |  |
| Mesna |  |  |  |
| Pyridoxine (hydrochloride) |  |  |  |
| Rasburicase |  |  |  |
| Corticosteroid (eye drop) |  |  |  |