

**Supplementary Materials:**

**Figure S1.** Questionnaire concerning the treatment of chronic neuropathic (or mixed) pain in children (the state of affairs).

**Information concerning the practitioner:**

(Your age is:) \_\_\_\_\_ years

(Sex:)  F  M

Your profession:

- general practitioner/family doctor
- pediatrician
- pediatric oncologist
- anesthesiologist
- pediatric anesthesiologist
- pediatric anesthesiologist painspecialist
- neurologist
- pediatric neurologist
- rehabilitation specialist
- clinical pharmacologist
- other: : \_\_\_\_\_

You work in:

- general practice
- public hospital
- private hospital
- academic hospital
- pediatric hospital (including academic pediatric hospital)
- rehabilitation clinic
- other: : \_\_\_\_\_

-Location of practice (name of hospital): \_\_\_\_\_

Country of practice: \_\_\_\_\_

How do you define "**chronic pain**" in your practice?

- Pain lasting more than 3 months
- Pain which persists past the time of normal healing
- Other: \_\_\_\_\_

-In your hospital, who are involved in treating children with all causes of chronic pain ? (more options possible)

- (pediatric) anesthesiologist
- (pediatric) anesthesiologist-pain specialist
- pediatrician
- pediatric oncologist
- pediatric neurologist
- rehabilitation specialist
- specialized pain nurse
- psychologist
- physiotherapist
- other:  : \_\_\_\_\_

-Is there a dedicated "pain team"?  Yes  No

-How much time (%) of your working week do you treat children with chronic pain (pain lasting more

than 3 months) every week ? \_\_\_\_\_%

-On average where do you treat children with chronic pain ?

Clinic \_\_\_\_\_%

In a special policlinic or outdoor department \_\_\_\_\_%

-On average how many patients in each age group do you see in a year with chronic (= continuous or recurrent pain of more than 3 months) neuropathic or mixed pain ?

3 months - < 3 years: \_\_\_\_\_

3 years - 7 years: \_\_\_\_\_

8 years – 18 years: \_\_\_\_\_

-Among patients in each age group what is the distribution between chronic neuropathic and mixed pain?

	<u>Neuropathic pain</u>	<u>Mixed pain</u>
3-months - < 3 years:	_____%	_____%
3 years - 7 years:	_____%	_____%
8 years – 18 years:	_____%	_____%

-In your practice, what is the usual frequency of clinical visits for neuropathic pain evaluation?

- i.  every 4 weeks
- ii.  every 6 weeks
- iii.  every 3 months
- iv.  every 6 months
- v.  upon request
- vi.  other *please specify* : \_\_\_\_\_

**Assessment and diagnosis:**

-How do you diagnose neuropathic or mixed pain in children ? (more options possible)

based on history

based on physical examination

based on underlying disease

based on treatment for another disease

based on diagnostic tests

-do you use a specially developed questionnaire to establish the diagnosis ?

DN4 Douleur Neuropathique en 4 questions)

LANSS (Leeds Assessment of Neuropathic Symptoms and Signs)

NPQ (Neuropathic Pain Questionnaire)

Pain Detect

ID-Pain (Identify Pain)

-do you use an age-specific validated pain scale to evaluate pain intensity ?

Yes  No

If so, which one ? : \_\_\_\_\_

-do you use a scale for physical functioning or quality of life (e.g Ped'sQL) ?

Yes  No

If so, which one ? : \_\_\_\_\_

-do you use the IASP criteria to establish the diagnosis of neuropathic pain ?

*"pain initiated or caused by a primary lesion or dysfunction in the nervous system"?*

Yes  No

-do you use additional diagnostics to establish the diagnosis: neuropathic pain? (more than one option possible)

QST (Quantitative Sensory Testing) measurement

MRI

Nerve biopsy

EMG

-At your practice, which type of underlying clinical condition(s) are the most frequent among patients with neuropathic or mixed pain?

*Please select all applicable items:*

- i.  Phantom limb pain
- ii.  Spinal cord injury
- iii.  Trauma and postoperative neuropathic pain
- iv.  Burns
- v.  Effects of cancer diseases processes and treatment
- vi.  Autoimmune, degenerative or inflammatory neuropathies (Guillan-Barré syndrome, Charcot-Marie-Tooth disease, Multiple Sclerosis...)
- vii.  Infections (eg HIV infections, toxic effects of anti-retroviral therapy, post-herpetic neuralgia)
- viii.  Toxic and metabolic neuropathies (mercury, lead, mitochondrial disorders...)
- ix.  Hereditary neurodegenerative disorders (eg Fabry disease)
- x.  Complex regional pain syndrome
- xi.  Erythromelalgia
- xii.  Other *please specify* : \_\_\_\_\_

**Treatment:**

-Is there a written standard protocol regarding the management of neuropathic or mixed pain in your practice?

Yes

No

-Which medication do you use for the **initial** management of **Moderate** (painscore 4-6) neuropathic or mixed pain ?

Please select all applicable items by giving them a number in the order of choice:

**Neuropathic pain**

**Mixed pain**  
**in my country**

**Not available**

<u>Paracetamol:</u>	<input type="checkbox"/> Paracetamol	<input type="checkbox"/> Paracetamol	<input type="checkbox"/>
<u>NSAID's:</u>	<input type="checkbox"/> Ibuprofen	<input type="checkbox"/> Ibuprofen	<input type="checkbox"/>
	<input type="checkbox"/> Diclofenac	<input type="checkbox"/> Diclofenac	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>COX2-inhibitors:</u>	<input type="checkbox"/> Celecoxib	<input type="checkbox"/> Celecoxib	<input type="checkbox"/>
	<input type="checkbox"/> Etoricoxib	<input type="checkbox"/> Etoricoxib	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>Anticonvulsants:</u>	<input type="checkbox"/> Gabapentin	<input type="checkbox"/> Gabapentin	<input type="checkbox"/>
	<input type="checkbox"/> Carbamazepine	<input type="checkbox"/> Carbamazepine	<input type="checkbox"/>
	<input type="checkbox"/> Pregabalin	<input type="checkbox"/> Pregabalin	<input type="checkbox"/>
<u>Antidepressants:</u>	<input type="checkbox"/> Amitriptyline	<input type="checkbox"/> Amitriptyline	<input type="checkbox"/>
	<input type="checkbox"/> Nortriptyline	<input type="checkbox"/> Nortriptyline	<input type="checkbox"/>
	<input type="checkbox"/> SNRIs: _____	<input type="checkbox"/> SNRIs: _____	<input type="checkbox"/>
<u>Opioids</u>	<input type="checkbox"/> Tramadol	<input type="checkbox"/> Tramadol	<input type="checkbox"/>
	<input type="checkbox"/> Tapentadol	<input type="checkbox"/> Tapentadol	<input type="checkbox"/>
	<input type="checkbox"/> Morphine	<input type="checkbox"/> Morphine	<input type="checkbox"/>
	<input type="checkbox"/> Oxycodone	<input type="checkbox"/> Oxycodone	<input type="checkbox"/>
	<input type="checkbox"/> Fentanyl	<input type="checkbox"/> Fentanyl	<input type="checkbox"/>
	<input type="checkbox"/> Buprenorphine	<input type="checkbox"/> Buprenorphine	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>Anesthetics:</u>	<input type="checkbox"/> Ketamine	<input type="checkbox"/> Ketamine	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	

Topical medication:  Lidocaine  Lidocaine   
 Capsaicine  Capsaicine

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



-Which medication do you use for **the initial** management of **Severe** (painscore >7) neuropathic or mixed pain ?

Please select all applicable items by giving them a number in the order of choice:

**Neuropathic pain**

**Mixed pain**  
**in my country**

**Not available**

Paracetamol:       Paracetamol       Paracetamol     

NSAID's:       Ibuprofen       Ibuprofen     

Diclofenac       Diclofenac     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

COX2-inhibitors:       Celecoxib       Celecoxib     

Etoricoxib       Etoricoxib     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Anticonvulsants:       Gabapentin       Gabapentin     

Carbamazepine       Carbamazepine     

Pregabalin       Pregabalin     

Antidepressants:       Amitriptyline       Amitriptyline     

Nortriptyline       Nortriptyline     

SNRIs: \_\_\_\_\_       SNRIs: \_\_\_\_\_     

Opioids       Tramadol       Tramadol     

Tapentadol       Tapentadol     

Morphine       Morphine     

Oxycodone       Oxycodone     

Fentanyl       Fentanyl     

Buprenorphine       Buprenorphine     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Anesthetics:       Ketamine       Ketamine     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Topical medication:     Lidocaine                       Lidocaine                        
                                  Capsaicine                       Capsaicine                     

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

-Which medication do you **for second-line** therapy for **Moderate** neuropathic or mixed pain when first-line therapy is not sufficient (Add on) ?

Please select all applicable items by giving them a number in the order of choice:

**Neuropathic pain**

**Mixed pain**  
**in my country**

**Not available**

<u>Paracetamol:</u>	<input type="checkbox"/> Paracetamol	<input type="checkbox"/> Paracetamol	<input type="checkbox"/>
<u>NSAID's:</u>	<input type="checkbox"/> Ibuprofen	<input type="checkbox"/> Ibuprofen	<input type="checkbox"/>
	<input type="checkbox"/> Diclofenac	<input type="checkbox"/> Diclofenac	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>COX2-inhibitors:</u>	<input type="checkbox"/> Celecoxib	<input type="checkbox"/> Celecoxib	<input type="checkbox"/>
	<input type="checkbox"/> Etoricoxib	<input type="checkbox"/> Etoricoxib	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>Anticonvulsants:</u>	<input type="checkbox"/> Gabapentin	<input type="checkbox"/> Gabapentin	<input type="checkbox"/>
	<input type="checkbox"/> Carbamazepine	<input type="checkbox"/> Carbamazepine	<input type="checkbox"/>
	<input type="checkbox"/> Pregabalin	<input type="checkbox"/> Pregabalin	<input type="checkbox"/>
<u>Antidepressants:</u>	<input type="checkbox"/> Amitriptyline	<input type="checkbox"/> Amitriptyline	<input type="checkbox"/>
	<input type="checkbox"/> Nortriptyline	<input type="checkbox"/> Nortriptyline	<input type="checkbox"/>
	<input type="checkbox"/> SNRIs: _____	<input type="checkbox"/> SNRIs: _____	<input type="checkbox"/>
<u>Opioids</u>	<input type="checkbox"/> Tramadol	<input type="checkbox"/> Tramadol	<input type="checkbox"/>
	<input type="checkbox"/> Tapentadol	<input type="checkbox"/> Tapentadol	<input type="checkbox"/>
	<input type="checkbox"/> Morphine	<input type="checkbox"/> Morphine	<input type="checkbox"/>
	<input type="checkbox"/> Oxycodone	<input type="checkbox"/> Oxycodone	<input type="checkbox"/>
	<input type="checkbox"/> Fentanyl	<input type="checkbox"/> Fentanyl	<input type="checkbox"/>
	<input type="checkbox"/> Buprenorphine	<input type="checkbox"/> Buprenorphine	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>Anesthetics:</u>	<input type="checkbox"/> Ketamine	<input type="checkbox"/> Ketamine	<input type="checkbox"/>
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____	
<u>Topical medication:</u>	<input type="checkbox"/> Lidocaine	<input type="checkbox"/> Lidocaine	<input type="checkbox"/>

Capsaicine

Capsaicine

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

—

-Which medication do you use or add if the initial therapy for **Severe** neuropathic or mixed pain is not sufficient (Add on) ?

Please select all applicable items by giving them a number in the order of choice:

**Neuropathic pain**

**Mixed pain**  
**in my country**

**Not available**

Paracetamol:       Paracetamol       Paracetamol     

NSAID's:       Ibuprofen       Ibuprofen     

Diclofenac       Diclofenac     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

COX2-inhibitors:       Celecoxib       Celecoxib     

Etoricoxib       Etoricoxib     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Anticonvulsants:       Gabapentin       Gabapentin     

Carbamazepine       Carbamazepine     

Pregabalin       Pregabalin     

Antidepressants:       Amitriptyline       Amitriptyline     

Nortriptyline       Nortriptyline     

SNRIs: \_\_\_\_\_       SNRIs: \_\_\_\_\_     

Opioids       Tramadol       Tramadol     

Tapentadol       Tapentadol     

Morphine       Morphine     

Oxycodone       Oxycodone     

Fentanyl       Fentanyl     

Buprenorphine       Buprenorphine     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Anesthetics:       Ketamine       Ketamine     

Other: \_\_\_\_\_       Other: \_\_\_\_\_

Topical medication:  Lidocaine  Lidocaine   
 Capsaicine  Capsaicine

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

-Do you use a titration schedule for the medication ?

If yes, for which one ?

Please select all applicable items:

<u>Paracetamol:</u>	<input type="checkbox"/> Paracetamol	<input type="checkbox"/> Paracetamol
<u>NSAID's:</u>	<input type="checkbox"/> Ibuprofen	<input type="checkbox"/> Ibuprofen
	<input type="checkbox"/> Diclofenac	<input type="checkbox"/> Diclofenac
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____
<u>COX2-inhibitors:</u>	<input type="checkbox"/> Celecoxib	<input type="checkbox"/> Celecoxib
	<input type="checkbox"/> Etoricoxib	<input type="checkbox"/> Etoricoxib
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____
<u>Anticonvulsants:</u>	<input type="checkbox"/> Gabapentin	<input type="checkbox"/> Gabapentin
	<input type="checkbox"/> Carbamazepine	<input type="checkbox"/> Carbamazepine
	<input type="checkbox"/> Pregabalin	<input type="checkbox"/> Pregabalin
<u>Antidepressants:</u>	<input type="checkbox"/> Amitriptyline	<input type="checkbox"/> Amitriptyline
	<input type="checkbox"/> Nortriptyline	<input type="checkbox"/> Nortriptyline
	<input type="checkbox"/> SNRIs: _____	<input type="checkbox"/> SNRIs: _____
<u>Opioids</u>	<input type="checkbox"/> Tramadol	<input type="checkbox"/> Tramadol
	<input type="checkbox"/> Tapentadol	<input type="checkbox"/> Tapentadol
	<input type="checkbox"/> Morphine	<input type="checkbox"/> Morphine
	<input type="checkbox"/> Oxycodone	<input type="checkbox"/> Oxycodone
	<input type="checkbox"/> Fentanyl	<input type="checkbox"/> Fentanyl
	<input type="checkbox"/> Buprenorphine	<input type="checkbox"/> Buprenorphine
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____
<u>Anesthetics:</u>	<input type="checkbox"/> Ketamine	<input type="checkbox"/> Ketamine
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____
Topical medication:	<input type="checkbox"/> Lidocaine	<input type="checkbox"/> Lidocaine

Capsaicine

Capsaicine

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

—

-In case you use Gabapentin as initial medication or second-line(add on) medication what is your initial starting dose, what is your target dose for maintenance and what is your maximum dose ?

Starting dose: \_\_\_\_\_mg/kg/day

Target dose: \_\_\_\_\_mg/kg/day

Max dose: \_\_\_\_\_mg/kg/day

-Once medication is effective, how long do you generally treat the patient before you decide to reduce or stop medication ?

\_\_\_\_\_ weeks

-In case the initial medication is **not** effective, how long do you generally treat the patient before you decide to add on medication ?

\_\_\_\_\_ weeks

-In case neither the initial medication nor the add-on medication is effective, how long you treat the patient before you decide to stop the medication ?

\_\_\_\_\_ weeks

-Would you agree to change your first-line medication for neuropathic or mixed pain treatment to participate in a research protocol concerning the treatment of average or severe chronic neuropathic pain in children ?



Yes, I agree

No, I do not agree to change medication

No, I agree to change medication but this would not be feasible in my practice

Comments: \_\_\_\_\_

\_\_\_\_\_

-In your practice, do you use other (non-pharmacological) approaches for chronic neuropathic or mixed pain?

Yes

No

*If yes, then could you please indicate which non-pharmacological approaches are usually privileged in your practice?*

**Neuropathic pain**

**Mixed pain**

Transcutaneous electric nerve stimulation

Transcutaneous electric nerve stimulation

Iontophoresis

Iontophoresis

Cognitive behavioral therapy

Cognitive behavioral therapy

Psychological and occupational therapy

Psychological and occupational therapy

EMDR

EMDR

(Eye Movement Desensitization and Reprocessing)

Physiotherapy

Physiotherapy

Hypnosis

Hypnosis

Other: \_\_\_\_\_

Other: \_\_\_\_\_