Paediatric palliative care is an emerging interest among physicians. In order to develop paediatric palliative care services in a logical and evidence-based manner, it is important to better define who needs this type of care. This survey aims to establish which children, in Canada, are perceived by their paediatricians to need specialist palliative care input, and what they feel that input should ideally provide. Survey results could inform on best practices for development in paediatric palliative care services.

Your contribution is greatly appreciated.

1. **What is your definition of palliative care?**
   
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

2. **For what types of conditions do you think palliative care is needed? (Check all that apply)**
   
   ____ Conditions for which curative treatment is possible but may fail (e.g., advanced or progressive cancer, complex and severe congenital heart disease)
   
   ____ Conditions requiring intensive long-term treatment aimed at maintaining quality of life (e.g., severe epidermolysis bullosa, severe immunodeficiencies, renal failure in which dialysis and/or transplantation are not indicated, muscular dystrophy)
   
   ____ Progressive conditions in which treatment is exclusively palliative after diagnosis (e.g., progressive metabolic disorders, certain chromosomal abnormalities such as trisomy 13 or 18)
   
   ____ Conditions involving severe, non-progressive disability, causing extreme vulnerability to health complications (e.g., severe cerebral palsy with recurrent infections or difficult to control symptoms, extreme prematurity, severe brain malformation)
   
   ____ Other(s), specify: _____________________________________________________________________________________

3. **Over the past month, how many children/youth have you seen who had any kind of palliative care need?**
   
   Of these patients: how many did you care for directly? _______ how many did you refer to another consultant? _______
   
   how many did you refer to a chronic care facility? _______

4. **What are the palliative care needs of your patients? (Check all that apply)**
   
   ____ Coordination of services in the community
   
   ____ Physical symptom management
   
   ____ Support for family (psychological, emotional, spiritual)
   
   ____ Support for child (psychological, emotional, spiritual)
   
   ____ Practical/financial support
   
   ____ Respite care: home____ chronic care facility____ other, specify:___________________________________________
   
   ____ Care at the time of death
   
   ____ Bereavement care
   
   ____ Discussion of prognosis with child
   
   ____ Discussion of prognosis with family
   
   ____ Other, specify: ______________________________________________________________

5. **Do you feel your patients are receiving all the services you have identified?**
   
   Yes____ No____
   
   If no, explain:__________________________________________________________________________________________
   
   __________________________________________________________

6. **Do you have access to the following? (Check all that apply)**
   
   Hospital or university-based palliative care: team____ → paediatric____ adult____ both____
   
   services____ → paediatric____ adult____ both____
   
   Community palliative care: team____ → paediatric____ adult____ both____
   
   services____ → paediatric____ adult____ both____
   
   Other, specify:________________________________________________________________________________________

7. **As a practicing physician, specify the supports you require to manage your patients with palliative care needs:**
   
   __________________________________________________________
   
   __________________________________________________________

Please return this survey with your monthly reporting form. Thank you for your participation.

09/2013