

# Survey

## Impacts of the COVID-19 pandemic on children with medical complexity

Your contribution is greatly appreciated.

1. Do you provide care for children with medical complexity (CMC)\* as part of your clinical practice?

\* CMC have chronic conditions with high family-identified needs (e.g., need for substantial care in the home) associated with **fragility** (e.g., frequent hospitalizations), **technology-dependence** (e.g., oxygen, enteral feeding tube, tracheostomy), and the **need for multiple care providers** (e.g., specialists, community providers, and home care services). An example would be a child with a developmental disability, seizures and dystonia, requiring G-tube feeds, with two previous admissions to hospital in the past year. CMC include those not yet discharged from hospital (e.g., premature infants in the neonatal intensive care unit), but exclude children who have high family-identified needs without associated medical complexity (e.g., children with autism).

Yes  No **If no, thank you for completing the survey.**

2. Which of the following best describes your practice?

General paediatrician  Paediatric subspecialist, specify: \_\_\_\_\_

Other, specify: \_\_\_\_\_

3. What is your practice setting? (Select all that apply)

a)  Urban  Suburban  Rural/Remote

b)  Academic  Non-academic

c)  Inpatient hospital  Emergency/Urgent care centre  Outpatient clinic  Private office/Community setting

4. Provide the first three digits of the postal code of the practice where you spend the majority of your time: \_\_\_ \_\_\_ \_\_\_

5. How many years have you been in independent practice? \_\_\_\_\_ years

6. Approximately what proportion of your clinical time is dedicated to the care of CMC? \_\_\_\_\_ %

### Healthcare delivery

7. Have you encountered CMC who experienced an adverse health outcome (e.g., preventable hospitalization) due to a COVID-19 pandemic-related disruption in healthcare delivery (e.g., interrupted primary care access)?  Yes  No

a) *If yes, how many?* \_\_\_\_\_

b) *If yes, and you have encountered one patient only, please indicate all related outcomes with "1".*

*If yes, and you have encountered multiple patients, please rank all related outcomes in order of frequency, starting with "1" = most common.*

*For outcomes not encountered, please mark with "0".*

\_\_\_ Hospital admission \_\_\_ Extended hospital admission \_\_\_ Unplanned surgery/Intervention \_\_\_ ICU admission \_\_\_ Death

\_\_\_ Loss of physical or developmental gains \_\_\_ Other, specify: \_\_\_\_\_

c) Any additional comments? \_\_\_\_\_

8. Have any COVID-19-related changes in healthcare delivery benefitted CMC in your care?  Yes  No

a) *If yes, list beneficial changes:* \_\_\_\_\_

### Family caregiving

9. Thinking about the families with CMC with whom you have interacted since the outset of the pandemic, have you encountered families with CMC whose **family caregiving** ability was significantly impacted by the COVID-19 pandemic (e.g., parental illness, loss of homecare)?  Yes  No  Unknown

**If no or unknown, proceed to question 10.**

a) *If yes, what percentage of families with CMC in your practice experienced significant challenges associated with family caregiving due to the COVID-19 pandemic?*  <20%  20–40%  41–60%  61–80%  >80%

b) *What were the most frequent challenges faced by family caregivers? Rank the following in order from most frequent to least frequent, with "1" being most frequent. For challenges not seen, mark with a "0".*

\_\_\_ Need for family caregiver self-isolation due to COVID-19 exposure or illness \_\_\_ Family caregiver mental illness/burnout

\_\_\_ School/respite services closure (resulting in increased total number of weekly hours at home) \_\_\_ Interrupted

rehabilitation \_\_\_ Loss of homecare \_\_\_ Increased financial stress \_\_\_ Other, specify: \_\_\_\_\_

c) Any additional comments? \_\_\_\_\_

## Homecare

10. Thinking about the families with CMC with whom you have interacted since the outset of the pandemic, have you encountered families with CMC who experienced disrupted **homecare** during the pandemic?  Yes  No  Unknown

**If no or unknown, proceed to question 11.**

- a) *If yes*, what percentage of families with CMC in your practice experienced disruptions in homecare delivery during the pandemic?  <20%  20–40%  41–60%  61–80%  >80%
- b) What were the most frequent homecare disruptions? Rank the following in order from most frequent to least frequent, with “1” being most frequent. For disruptions not seen, mark with a “0”.
- \_\_\_ Need for family self-isolation due to COVID-19 exposure/symptoms or infection \_\_\_ Decreased homecare availability
- \_\_\_ Homecare worker illness or need for self-isolation \_\_\_ Family choice to discontinue or limit homecare
- \_\_\_ Other, specify: \_\_\_\_\_
- c) Any additional comments? \_\_\_\_\_

## Medication and equipment supply

11. Did any CMC in your practice encounter difficulties accessing important supplies during the pandemic?

Yes  No  Unknown

**If no or unknown, proceed to question 12.**

- a) *If yes*, which important supplies were difficult to access? (Select all that apply)
- Medication  Medical equipment  Personal protective equipment  Hand sanitizer  Routine vaccinations
- Other, specify: \_\_\_\_\_
- b) Specify if difficulties were due to (select all that apply):
- Medication or supply shortage; specify: \_\_\_\_\_  Delays in prescribing; describe: \_\_\_\_\_
- Delays in dispensing; describe: \_\_\_\_\_  Other, specify: \_\_\_\_\_
- c) What was the most severe outcome associated with medication and equipment access difficulties? (Select one)
- Minor inconvenience (e.g., short delay, no change in care)
- Moderate issue (e.g., alternative medication or equipment sourced, no change in clinical status)
- Significant event (e.g., negative clinical outcome)  None
- d) *If a significant event* was experienced by one of your patients, provide additional details: \_\_\_\_\_
- e) *If a significant event* was experienced by one of your patients, did the negative clinical outcome result in (select all that apply):  Hospital admission  Unplanned surgery/intervention  ICU admission
- Death  Other, specify: \_\_\_\_\_
- f) Any additional comments? \_\_\_\_\_

## Education, including virtual learning, school supports, in-school delivery of nursing and therapies

12. What percentage of school-aged CMC in your practice attended school in-person in September 2020?

<20%  20–40%  41–60%  61–80%  >80%  Unknown

a) What percentage of school-aged CMC in your practice attended school in-person in previous years (non-COVID-19 years)?

<20%  20–40%  41–60%  61–80%  >80%  Unknown

13. Were CMC excluded from in-person learning when children without medical complexity were given the option to attend class?

Yes  No  Unknown

Any additional comments? \_\_\_\_\_

14. Do CMC in your practice typically receive any healthcare services via the education system (e.g., access to rehabilitation services, school nursing)?  Yes  No  Unknown

*If yes*, were such services transferred to home and/or community during periods of virtual learning?  Yes  No  Unknown

15. Did public health advice preclude any children from attending school (e.g., children whose care involves aerosol generating medical procedures)?  Yes  No  Unknown

*If yes*, describe: \_\_\_\_\_

16. Have you encountered issues relating to school closure that are particularly relevant to CMC (e.g., transportation)?  Yes  No

*If yes*, describe: \_\_\_\_\_

17. Any additional comments? \_\_\_\_\_

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

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