Case Report Form: Canadian COVID-19 Palliative Registry

Start of Block: Palliative COVID-19 Provider Information

Q1 Clinician/Provider/Reporter Name

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Q2 Clinician/Provider/Reporter Email address

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q3 Clinician/Provider/Reporter practice location

* Hospital (1)
* Hospice or Palliative Care Unit (2)
* Physician Group, Office Practice, or Clinic (3)
* Long-term Care Facility (4)
* Home Care or Home Health Agency (5)
* Independent Organization (6)
* Other (7)

Q4 City of organization

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q5 Province

* Alberta (1)
* British Columbia (2)
* Manitoba (3)
* Maritime Provinces: New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador (4)
* Ontario (5)
* Quebec (6)
* Saskatchewan (7)

End of Block: Palliative COVID-19 Provider Information

Start of Block: Palliative COVID Patient Information

Q6 What is the patient’s current gender identity?

* Female (1)
* Male (2)
* Other

Q7 What is the patient’s age?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q8 Does the patient identify as belonging to one or more of the following ethnicity, race or special populations categories? Select all that apply.

* White (1)
* Black or African Canadian (2)
* Asian (3)
* Arab (4)
* West Asian / Middle Eastern (5)
* Native Canadian / Aboriginal / First Nations /Original peoples of this land (6)
* Vulnerably housed, homeless (7)
* Incarcerated/Prison inmate (8)
* Unknown or prefer not to answer (9)

Q9 The patient's COVID-19 status was confirmed or suspected?

* Under investigation/ Suspected (1)
* Confirmed (2)

Q10 COVID-19: Treatment (Only include medications or interventions given as treatment for this infection). Select all that apply.

* No treatment except symptomatic management (1)
* Supplemental oxygen (2)
* Medications including Remdesivir, antivirals, anitmalarials, IL-6 inhibitors, glucocorticoids, IVIG, plasma, those in clinical trials, etc. (3)
* Hospitalization (4)
* ICU Admission (5)
* Ventilation (6)

Q11 COVID Symptoms- Select all that apply.

* No known symptoms (1)
* Fever (2)
* Malaise/fatigue (3)
* Irritability/confusion (4)
* Headache (5)
* Sore throat (6)
* Runny nose (7)
* Cough (8)
* Shortness of breath (9)
* Chest pain (10)
* Joint pain (11)
* Muscle aches (12)
* Abdominal pain (13)
* Diarrhea, vomiting or nausea (14)
* Loss of smell (anosmia) (15)
* Altered sense of taste (dysgeusia) (16)
* Rash (17)

Q12 COVID-19: Complications- Select all that apply.

* No known complications (1)
* Acute Respiratory Distress Syndrome or ARDS (2)
* Sepsis (3)
* Myocarditis or new heart failure (4)
* Concomitant or secondary infection (e.g. Influenza) (5)
* Other serious complication (6)

Q13 Infection Acquisition: In the 14 days before onset of illness did the patient have any of the following?

* History of travel to an area with documented cases of COVID-19 infection (1)
* Close contact with a confirmed or probable case of COVID-19 infection (2)
* Presence in a healthcare or long-term care facility where COVID-19 infections have been managed (3)
* None of the above (community acquired) (4)
* Unknown (5)

Q14 Please select the category that best describes the patient’s location during your care

* Hospital- General Floor (1)
* Hospital – ICU (includes MICU, SICU, TICU, CICI, Neuro ICU, PICU) (2)
* Emergency Department (3)
* Outpatient Clinic (4)
* Long term Care (5)
* Palliative Care Unit or Hospice (6)
* Retirement Home/Assisted Living Facility (7)
* Home (8)
* Other (9)

Q15 How did you see the patient?

* Telehealth (1)
* In-person (2)
* Mix of both (3)

Q16 Please select the diagnosis category that best reflects the patient’s primary underlying serious illness diagnoses in addition to COVID-19. Only select those currently active or contributory to patient's status.  If the patient was previously well, please mark none. If multi-factorial- select those that apply (NOTE: comorbidities are listed in another question)

* None (patient was previously well with no serious illness) (1)
* Cancer (solid tumor) (2)
* Cancer (Hematological) (3)
* Cardiovascular (4)
* Pulmonary (5)
* Gastrointestinal (6)
* Hepatology (7)
* Renal (8)
* Dementia (9)
* Neurology (includes Neuromuscular or non-dementia (10)
* Infectious (11)
* Trauma (12)
* Vascular (13)
* Metabolic/Endocrine (14)
* Genetic/ Chromosomal (15)
* Hematology (non-cancer) (16)
* Frailty (17)
* Unknown (18)

Q17 Non-COVID-19 Illness/disease activity at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

* Remission or stable (1)
* Minimal progression or low disease activity (2)
* Moderate disease progression or activity (3)
* Severe or high disease progression or activity (4)
* Unknown (5)

Q18 Comorbidities- Select all that apply.

* None (1)
* Lung disease (COPD/asthma/ILD) (2)
* Diabetes (3)
* Morbid obesity (BMI 40+) (4)
* Hypertension (5)
* Cardiovascular disease (coronary artery disease, congestive heart failure, pulmonary hypertension) (6)
* Renal disease (7)
* Cancer (8)
* Organ transplant recipient (9)
* Immunodeciency (10)
* Liver disease (11)
* Chronic neurological or neuromuscular disease (12)
* Psychiatric condition (e.g., schizophrenia, bipolar disorder) (13)
* Pregnancy (14)
* Post-partum (< 6 weeks) (15)
* Unknown (16)

Q19 What was the patient palliative performance status just prior to COVID infection (0-100%)

* 0% (1)
* 10% (2)
* 20% (3)
* 30% (4)
* 40% (5)
* 50% (6)
* 60% (7)
* 70% (8)
* 80% (9)
* 90% (10)
* 100% (11)
* Unknown (12)

Q20 What was the **lowest** patient palliative performance status during COVID infection (0-100%)

* 0% (1)
* 10% (2)
* 20% (3)
* 30% (4)
* 40% (5)
* 50% (6)
* 60% (7)
* 70% (8)
* 80% (9)
* 90% (10)
* 100% (11)
* Unknown (12)

Q21 What was the reason for palliative care involvement?

* Physical Symptom Management (1)
* Psychosocial support to patient (2)
* Decision Making (includes Goals of Care) (3)
* Providing support to family (4)

Q22 Was Advance Care Planning/Goals of Care discussed with the patient prior to COVID-19 infection?

* Yes (1)
* No (2)
* Unknown (3)

Q23 Was Advance Care Planning/Goals of Care discussed after confirmation of/suspected COVID-19 infection but prior to palliative care involvement?

* Yes (1)
* No (2)
* Unknown (3)

Q24 What was the formally indicated status of the patient during care, with respect to the desire for resuscitative efforts.

* Full Cardiopulmonary Resuscitation (CPR/Intubation/ICU Transfer) (1)
* Modified resuscitation for respiratory distress: Intubation and mechanical ventilation, No CPR (2)
* Allow Natural Death (3)
* Unknown (4)

Q25 Symptoms you or your team managed

|  |  |  |
| --- | --- | --- |
|  | Symptom related to COVID (1) | Symptom related to Palliative Diagnoses (2) |
| Pain (1) |  |  |
| Malaise/fatigue (2) |  |  |
| Delirium/Irritability/confusion (3) |  |  |
| Cough (4) |  |  |
| Shortness of breath (5) |  |  |
| Vomiting or Nausea (6) |  |  |
| Constipation (7) |  |  |
| Anxiety (8) |  |  |
| Depression (9) |  |  |
| Poor sleep (10) |  |  |
| Appetite |  |  |
| General Weakness |  |  |

Q26 Palliative Treatments you or your team Started/Titrated/Stopped

|  |  |  |  |
| --- | --- | --- | --- |
|  | Started (1) | Titrated (2) | Stopped (3) |
| Morphine/Hydromorphone (1) |  |  |  |
| Oxycodone (2) |  |  |  |
| Fentanyl/Sufentanyl (3) |  |  |  |
| Midazolam (4) |  |  |  |
| Other benzos (lorazepam, diazepam) (5) |  |  |  |
| Methotrimeprazine (6) |  |  |  |
| Phenobarbitol (7) |  |  |  |
| Loxapine (8) |  |  |  |
| Haloperidol (9) |  |  |  |
| Glucocorticoids (10) |  |  |  |
| NSAIDs (11) |  |  |  |
| Glycopyrronium or Scopolamine (12) |  |  |  |
| Palliative Sedation (13) |  |  |  |

Q27 What is your clinical impression of palliative treatment effectiveness (i.e. the palliative care provided you and/or your team)?

* Yes (1)
* Unclear (patient died prior to follow-up) (2)
* No (3)

Q28 Were palliative treatment options affected by drug shortages?

* Yes (1)
* No (2)

Q29 Did any of the following factors influence the patient's care or location of care

* Speed of patient deterioration (1)
* Lack of ACP/GoC ie goals of care clarity (2)
* Availability of PPE (3)
* Availability of medications (4)
* Availability of home care support (5)
* Availability of family/caregivers (6)
* Access to PCU or hospice placement for COVID positive patients (7)
* Restrictive institutional visitation policies

Q30 Patient Outcome

* COVID infection Resolved (1)
* Patient Died (2)

Q31 If the COVID infection resolved, what was the palliative performance status at last visit

* 10% (1)
* 20% (2)
* 30% (3)
* 40% (4)
* 50% (5)
* 60% (6)
* 70% (7)
* 80% (8)
* 90% (9)
* 100% (10)

Q32 If COVID infection resolved what is the patient's current plan of care?

* Continues to pursue a palliative approach to care and will be followed by a palliative care provider (1)
* No plans for palliative care follow up (2)

Q33 If COVID infection resolved what is the patient's current discharge plan?

* Hospital (1)
* Long term Care (2)
* Palliative Care Unit or Hospice (3)
* Retirement Home/Assisted Living Facility (4)
* Home (5)
* Other (6)

Q34 If deceased, where did the patient die?

* Hospital- General Floor (1)
* Hospital – ICU (includes MICU, SICU, TICU, CICI, Neuro ICU, PICU) (2)
* Emergency Department (3)
* Outpatient Clinic (4)
* Long term Care (5)
* Palliative Care Unit or Hospice (6)
* Retirement Home/Assisted Living Facility (7)
* Home (8)
* Other (9)

Q35 Did any of the following factors influence the patient's location of death

* Speed of patient deterioration (1)
* Lack of ACP/GoC ie goals of care clarity (2)
* Availability of PPE (3)
* Availability of medications (4)
* Availability of home care support (5)
* Availability of family/caregivers (6)
* Access to PCU or hospice placement for COVID positive patients (7)
* Restrictive institutional visitation policies (8)

Q36 If the patient died at home, was appropriate personal protective equipment (masks, face shields, gloves, etc.) made available for clinicians and family/caregivers?

|  |  |  |
| --- | --- | --- |
|  | Yes adequate PPE was available (1) | No adequate PPE was not available (2) |
| Clinicians (1) |  |  |
| Family/Caregivers (2) |  |  |

Q37 Do you feel this patient received goal-concordant care?

* Definitely yes (1)
* Probably yes (2)
* Might or might not (3)
* Probably not (4)
* Definitely not (5)

Q38 What challenges or ethical barriers did you encounter in caring for this patient? Please do not include any patient identifiable information in your response.

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Q39 Thank you for adding to the patient to the registry.  We welcome any comments you may have.

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End of Block: Palliative COVID Patient Information