**COVID-19 Palliative Registry**

**PROJECT DESIGN**

The COVID-19 Palliative Registry aims to create a prospective national registry of baseline characteristics and clinical outcomes of patients with suspected or laboratory confirmed COVID-19 and life-limiting illnesses for completion by palliative health care professionals over 18 months. We will capture clinician reporter and patient information via Qualtrics, an online survey program. Data will be collected across Canada and reported as it is collected via a publicly available website. This will allow for provincial and national health care administrators and providers to rapidly use this data in their quality improvement and surveillance efforts. This information will improve palliative care provided during the COVID-19 pandemic and support the development of health care system capacity and preparedness for future public health emergencies.

Similar initiatives have been started during the COVID-19 pandemic to inform care for other patient populations. Specifically, health care institutions, research collaboratives and societies have developed COVID-19 reporting strategies for people with inflammatory bowel disease (SECURE-IBD; https://covidibd.org/), rheumatologic conditions (https://rheum-covid.org/) and cancer (https://www.asco.org/asco-coronavirus-information/coronavirus-registry). We have adopted a similar project design to ensure that our initiative is similarly successful.

**METHODOLOGY**

**Case Report Form (CRF)**

A short online Case Report Form (CRF) has been created (Appendix A). It is designed to balance collecting a useful dataset with speed and ease of data input. It does not contain any Personal Health Identifiers (PHI).

*Clinician reporter demographics* will include name, city, province, workplace setting and email address.

*Patients demographics and data points* will include age, gender, race, ethnicity, geography, underlying life-limiting illnesses and status during COVID-19 infection and other comorbidities symptoms, performance status, disease progression/activity, race, ethnicity, geography, locations of care and death.

*Data related to COVID-19* that will be collected include COVID-19 testing status, treatments provided, symptoms, complications, infection acquisition.

*Palliative care* information collected will include how care was delivered (in-person or telehealth), palliative performance status, reasons for involvement, advance care planning/goals of care discussions, symptom management and medications provided.

*Resources:* We will also examine the impact of resource availability (medications, home care support, PPE, social supports, palliative care beds) on the provided palliative care and location of care and death.

The CRF will be piloted with 20 patient cases to ensure suitability of questions and ease of data input.

Once completed the CRF will be automatically uploaded to Qualtrics platform (<https://www.qualtrics.com/>) to collect and collate the data. Qualtrics is a widely used secure web application used by thousands of academic and healthcare institutions across the world.

The CRF link and project information will be hosted on our partner website <http://www.virtualhospice.ca/.> This site will include information about the project aims, objectives and also a place for reporting aggregate data as data is collected.

**Participating Practices or Providers**

Any palliative care clinician may participate and report patients into the COVID-19 Palliative Registry. These clinicians will include primary palliative care clinicians and specialists with focused practices in palliative care. Primary palliative care clinicians are defined as clinicians who do not specialise in palliative care, such as family physicians, oncologists, internists, geriatricians and respirologists. Clinicians who provide palliative care in all sectors can report data, including acute care, long-term care, complex continuing care, home care, palliative care units, hospice and the community.

Clinicians will be asked to report about patients with a life-threatening illness who have a suspected or laboratory confirmed COVID-19 infection and are being treated by a palliative care clinician within Canada. Clinician reporters will be asked to enter data into the registry only after a minimum of 7 days or clinician has determined that sufficient time has passed to observe the disease course through resolution of acute illness or death of the patient. Once a reporter completes a survey they will not be able to access the survey again or update it for the same patient.

**Research Ethics Approval**

This study is a quality improvement study. Unfortunately, due to different provincial legislation concerning quality improvement studies across Canada we cannot provide clear national guidance as to whether collaborators can receive a QI exemption from research ethics board review, or not. For example, according to Ontario legislation, one cannot share any patient data [personal health information (PHI) or non-PHI] across institutions. For this reason, we have received Clinical Trials Ontario provincial REB approval (or separate institutional REB approval) for all Ontario sites. Each collaborating site will need to contact their local REBs to confirm if this project can proceed as a quality improvement study in their institution or require a traditional REB approval.

**KNOWLEDGE TRANSLATION AND DISSEMINATION**

**Reporting**

The COVID-19 Palliative Registry team will periodically create reports to share with participating practices and the general community. This will be hosted on our partner website <http://www.virtualhospice.ca/>. Reports will summarize frequency and severity of COVID-19 infection, COVID-19 interventions, overall and stratified by patient characteristics, such as disease, age and comorbidities. Changes in practices’ patterns of care, resources, and interactions with patients will also be evaluated and summarized. The team will strive to provide reports at least monthly. However, timing will depend on the number of cases reported to the registry, and the availability of subsequent outcome information.