

## **R065: CovPall-Connect. Evaluation of the COVID-19 pandemic response in palliative and end of life care: Connecting to boost impact and data assets.**

Palliative care is the medical approach aimed at helping wellbeing, and easing pain of people at the end of their life. Covid-19 has had a large impact on health care services. 1-4% of people have died from Covid-19, with over 100,000 UK deaths. The vulnerable groups that palliative care helps, are those most affected by Covid-19. The symptoms can be painful and stressful, but most of them are not well understood. This makes it hard for palliative care workers to change how they work in response to Covid-19. Our research hopes to assess the palliative care response to Covid-19.

In a project called CovPall we surveyed medical and nursing professionals about how they have managed and changed the way they work during Covid-19. We also collected information on patients' symptoms and their management. We want to use national data to boost findings from CovPall. We hope to allow use of CovPall data for other research.

Palliative care is an approach that aims to ease symptoms and improve wellbeing and for people living with life-limiting illnesses, who may be approaching the end of their life. The COVID-19 pandemic is placing an unprecedented strain on health care services. Although many people survive, an estimated 1 to 3% die from this disease. People with severe COVID-19 experience severe symptoms such as breathlessness, fatigue and agitation. There have been more than 100,000 UK deaths from COVID-19, with numbers still increasing. The conditions of the pandemic, such as lockdown, shielding, social distancing, has made care for people with advanced diseases and/or needing palliative care challenging.

The CovPall study is a rapid multinational observational study of palliative care during COVID-19, involving a cross-sectional on-line survey of hospice and specialist palliative services in the UK (adult & children, all settings, voluntary hospices, inpatient, home care, hospital palliative care teams) between April and July 2020. The survey used open and closed questions to ask about their practices and how these have changed, and their challenges and innovations.

CovPall study datasets included non-sensitive and non-personal data. The datasets include findings from Northern Ireland as reported by the service leads of palliative and end of life care services in Northern Ireland. The dataset includes information connected via an online survey about services offered before the pandemic experience with suspected or confirmed cases of COVID-19, how services have changed in response to COVID-19 (business, use of virtual technologies, advance care planning, bereavement, and supporting patients from disadvantaged social demographic communities, and effect on palliative care patients who do not have COVID-19), changes in specific services such as inpatient hospice services supported by volunteers, support for patients in their own homes, in care homes, and support for families. The CovPall dataset has also collected information on challenges and innovations in response to COVID-19 and details of symptom management and treatments used.

CovPall-Connect provides an opportunity for national data linkage to explore using ecological analyses, primarily regional, the palliative care response to COVID-19. Findings will boost CovPall study impact, inform national responses, and enhance data assets.

Through the National Core Studies (NCS) programme we will engage more widely with patients and carers, members of the public, and professionals, and also invite them to contribute to the wider programme.

The CovPall-Connect study links anonymised service level survey data from the CovPall study with routinely collected data from the four nations of the United Kingdom. We are requesting access to record level data sets spanning the pandemic period on Covid-19 and non-Covid-19 related mortality prevalence, admissions, discharges, business / social impacts to capture palliative care activity and link to service level data at regional level.

The research question we are addressing is: What is the relationship between regional Covid-19 palliative care responses and Covid-19 prevalence, mortality, admissions, discharges, business / social impacts?

Objectives:

1. To explore the feasibility of using palliative care survey data with national routinely collected Northern Ireland datasets across Northern Ireland, and compare these findings with datasets from Wales, Scotland and England, to understand the palliative care response to covid-19 pandemic.
2. To describe regional variation in Northern Ireland within palliative care service response to covid-19 (enhancing the findings from the CovPall study dataset which will be ingested into the TRE on e.g. busyness, service provision in care homes and care homes, shortages) and its relationship with characteristics derived from Northern Ireland datasets, such as population size, age, deprivation, ethnicity, and covid-19 prevalence.
3. To describe the relationship between palliative care services responses (captured by the CovPall study dataset e.g. busyness) and health outcomes, mortality, and hospital admissions during the first weeks of the covid-19 pandemic captured by Northern Ireland datasets at a regional level across the UK.
4. To examine factors associated with place of death during the Covid-19 pandemic at a regional level within Northern Ireland from datasets, to then be compared with findings from datasets for each nation (Wales, Scotland and England), including palliative care busyness across settings and deprivation from Northern Ireland datasets.