

# Information for patients with blood cancer & COVID-19

## What is a Registry?

Registry studies are conducted to gather more information about the best way to manage patients' illnesses. The **ASH RC study** is being conducted to collect information on the impact of COVID-19 on patients who are currently under treatment or have a history of treatment for a haematology malignancy.

## What is COVID-19?

COVID-19 is the disease caused by the novel SARS-2 coronavirus. For patients with a haematology diagnosis across Ireland, the COVID-19 outbreak is a major cause for worry and concern. They have been advised to cocoon as they may be at risk of severe COVID-19 infection. Their treatment is also being impacted.

## Who is organising the study?

The study is being organised by the American Society of Haematology Research Collaborative (ASH RC), a not-for-profit organisation which was founded in 2018 to improve the lives of people affected by blood diseases by fostering collaborative partnerships to accelerate progress in haematology.

## What is the ASH RC COVID-19 Registry?

ASH RC have launched a COVID-19 for Haematologic Malignancy registry that aims to gather data on patients with a haematologic malignancy (i.e. blood cancer such as lymphoma, leukaemia, and myeloma) who develop COVID-19. Patients with blood cancer may be at increased risk of infection as a direct result of both their cancer and their cancer treatment.

## Why we need your data

This is a new virus and there is a lack of information on the management of patients with blood cancer. The purpose of this registry is to quickly gather data and publish trends on the incidence and severity of COVID-19 amongst patients with a history of treatment for a blood cancer and patients who are currently undergoing active treatment for their blood cancer.

## What type of data is collected?

Medical staff will collect the following information from your medical charts:

- Personal information such as age group, gender, health background
- Cancer Information such as the type of blood cancer and what cancer treatment you are currently undertaking or have received in the past.
- COVID-19 information such as when and how you were diagnosed, what treatment you have had. It will also confirm if you remained at home and had your treatment at home or in hospital and the outcome of this treatment. Finally, it will confirm when you have recovered from COVID-19 and whether there has been any significant additional impacts to your cancer care.

**Your Name, Date of Birth, Hospital Number, Phone Number, Address or any other identifiable information about you will not be collected for this study.**

## If you want more information?

Talk to your doctor or nurse and they will explain the study in more detail to you and provide you with all the information you need. Further information on the ASH RC COVID-19 Registry may be found here:

<https://www.ashresearchcollaborative.org/s/covid-19-registry>