Welcome to the COVID-CF project in Europe

CF patient registries throughout Europe have collected data about people with CF who become infected with SARS-Cov-2, causing the illness COVID-19.

Countries that contribute annual data to the ECFS Patient Registry (ECFSPR; www.ecfs.eu/ecfspr) were invited to report COVID-19 case data of people with a confirmed diagnosis of CF. Centres reported data directly to the ECFSPR, and aggregated data was provided by national registries that use their own data-collection system. Here we present centralised, anonymised data, which we hope to update weekly.

It is possible that not all cases have been reported yet. Since the data is preliminary, incomplete, might change over time, and the number of cases is low, the information should not be used to direct clinical decisions. A more substantial statistical analysis will be performed and published later.

Definitions are provided for all the variables measured at the end of this report.

Summary (up to 16 October 2020)

Important update:

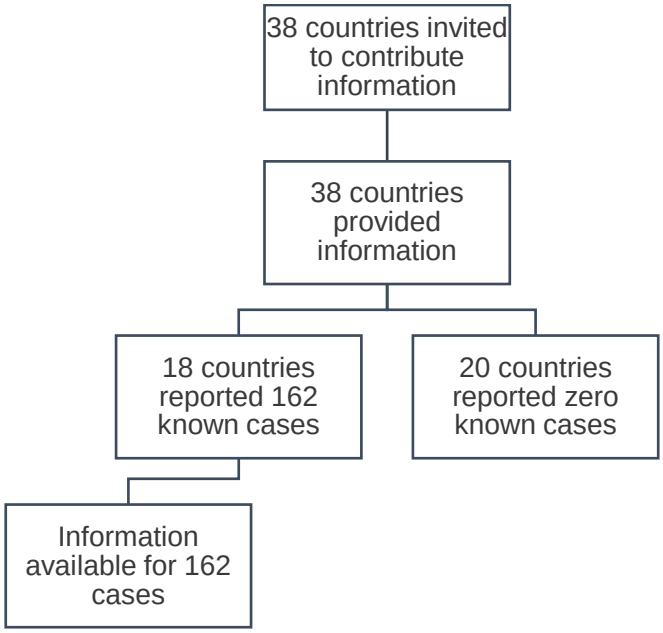
Since the last update, we have received more complete aggregate data from CF centres and national registries. However, many variables still have missing/unknown data – we have changed the graphs to reflect this. The database has been further cleaned to remove patients who did not have a PCR-confirmed diagnosis of infection with SARS-Cov-2. This is because serological antibody tests lack specificity for the SARS-Cov-2 virus compared to other coronaviruses circulating in the population. Aggregate data from national registries may still include patients who have only had an antibody test (without PCR confirmation).

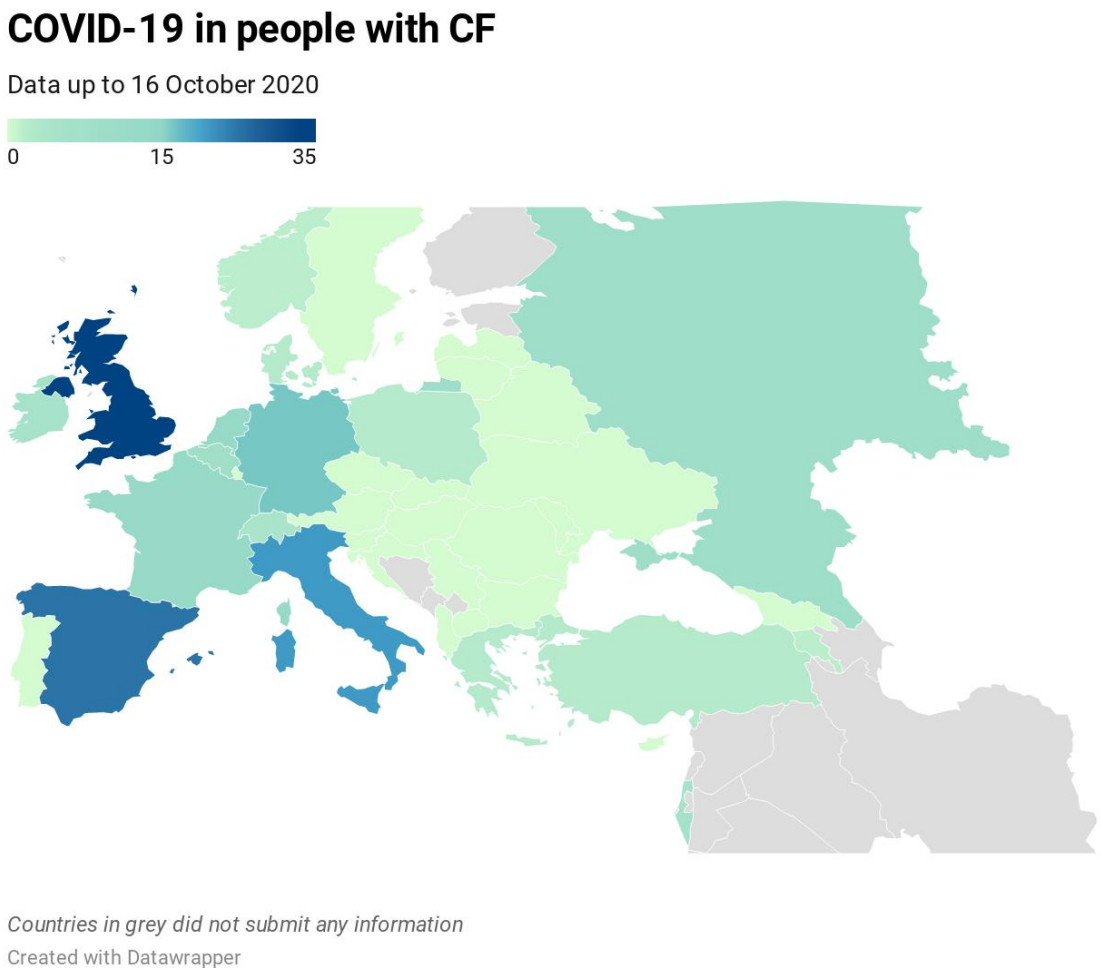
162	162	11	5
People with CF have confirmed COVID-19	Case data available	Needed intensive care	Died

- 2 critical cases
- The most common treatments were additional antibiotics (oral and intravenous) and azithromycin

Distribution in Europe

The following flow chart presents the number of countries that reported COVID-19 cases in people with CF by 16 October 2020.



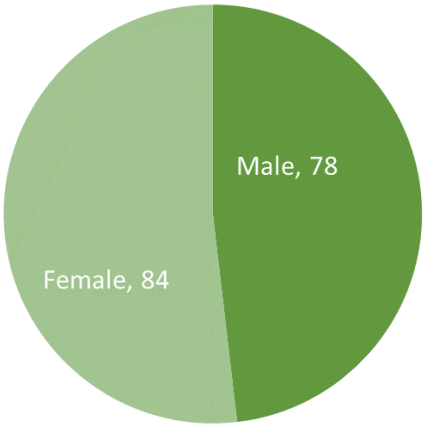


Summary data for the 162 cases with information

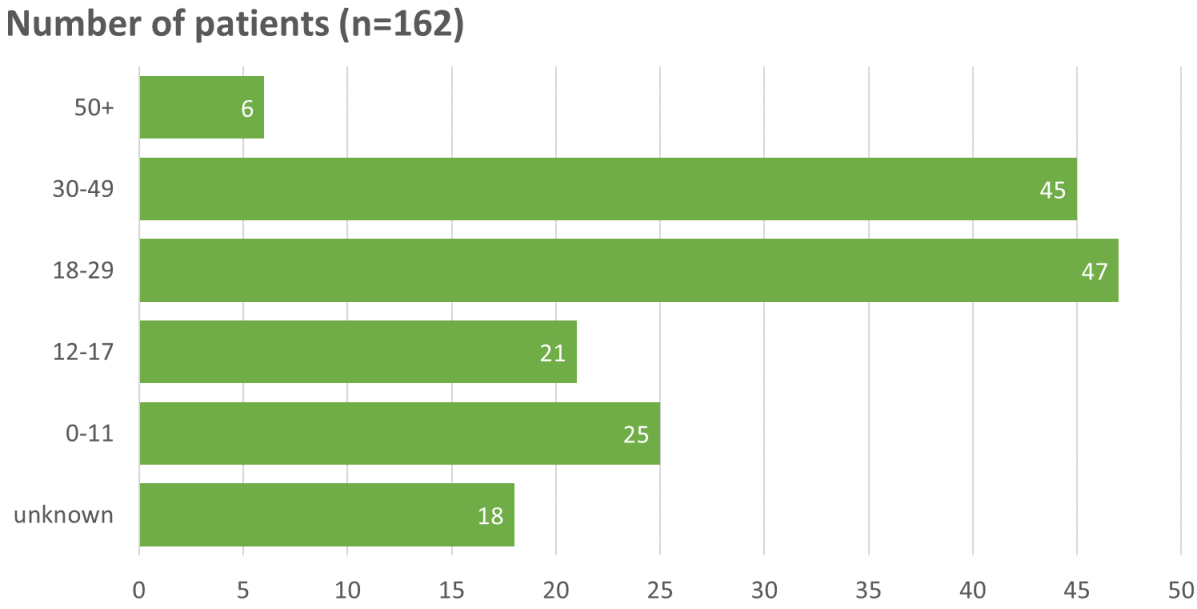
The rest of this report presents data for the 162 reported cases with at least partial data. If case reports were incomplete, the missing information has not been considered.

Demographics

Gender



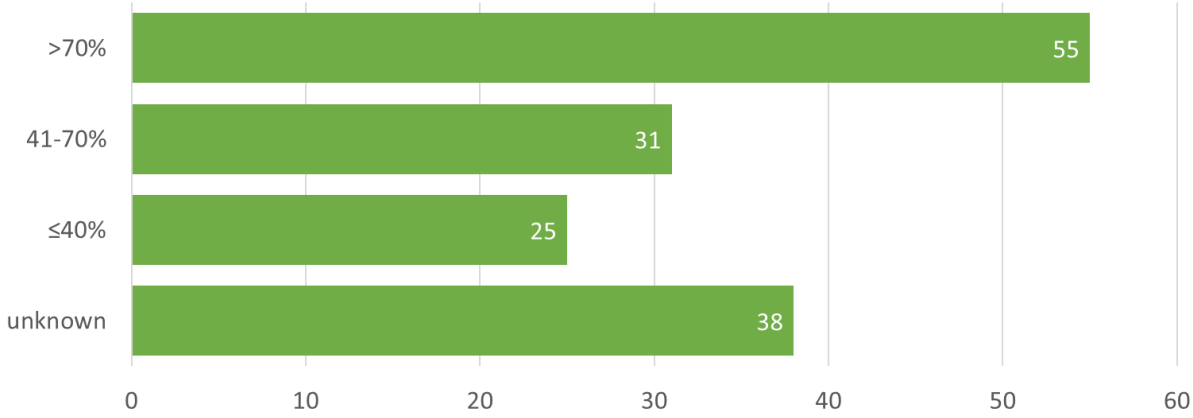
Age category (years)



Cystic fibrosis characteristics

Percent predicted FEV_1, by category

Number of patients (n=162)

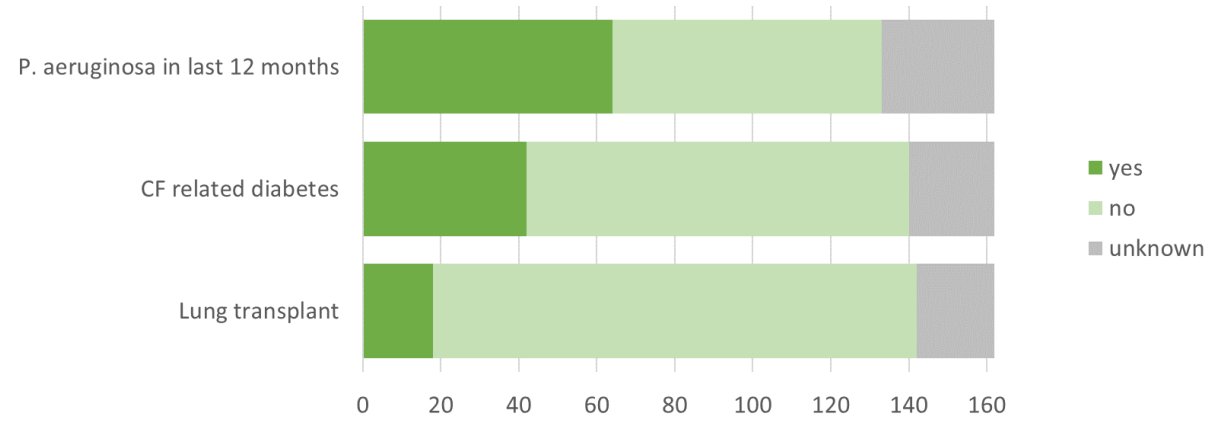


Note: ppFEV1 = percent predicted forced expiratory volume in one second.
*Percent predicted FEV1 was only calculated for patients aged 6 years and over

Other cystic fibrosis characteristics

Number of patients (n=162)

Patients could have between 0 and 3 of these characteristics

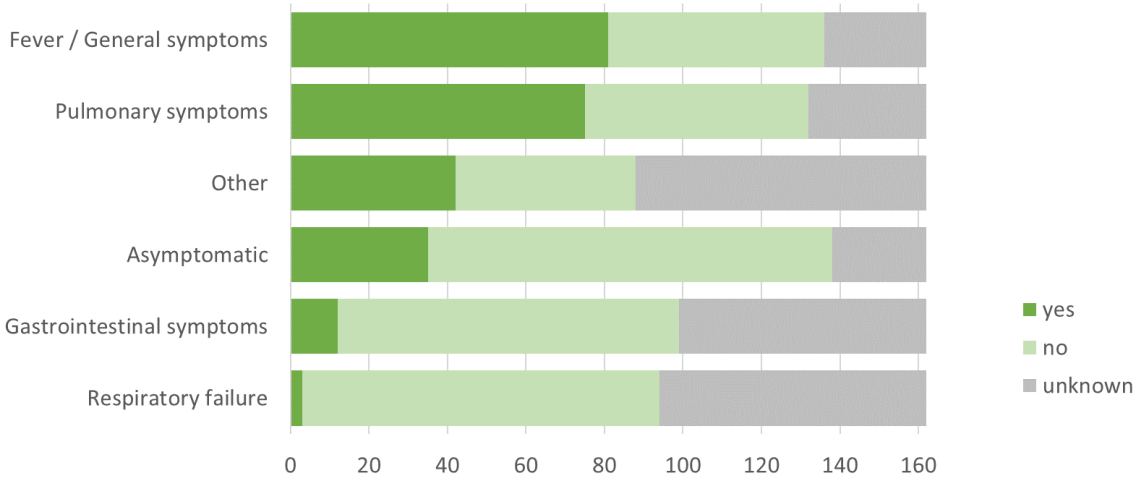


COVID-19 symptoms

Categories of symptoms

Number of patients (n=162)

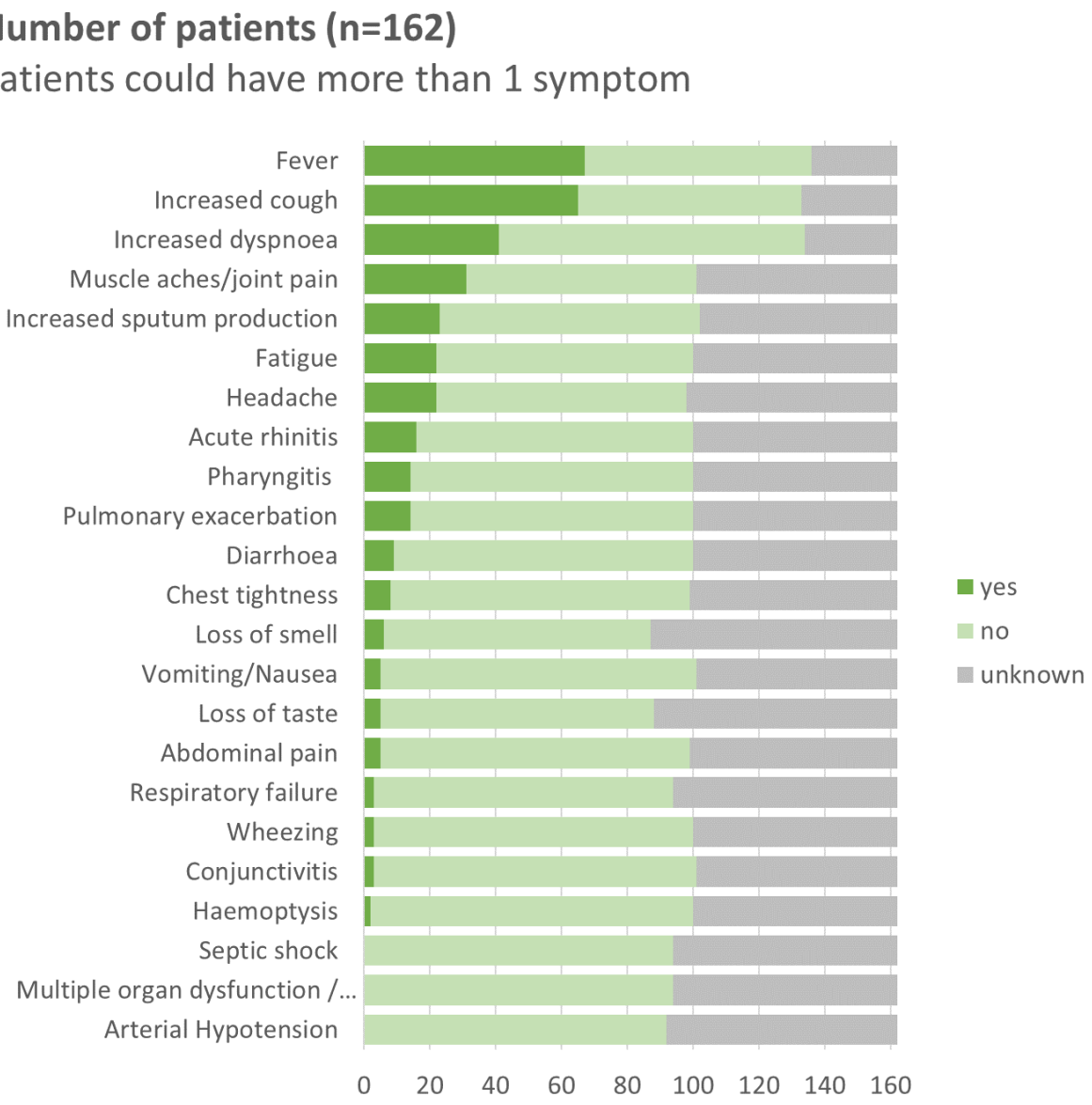
Patients could have symptoms in more than one category



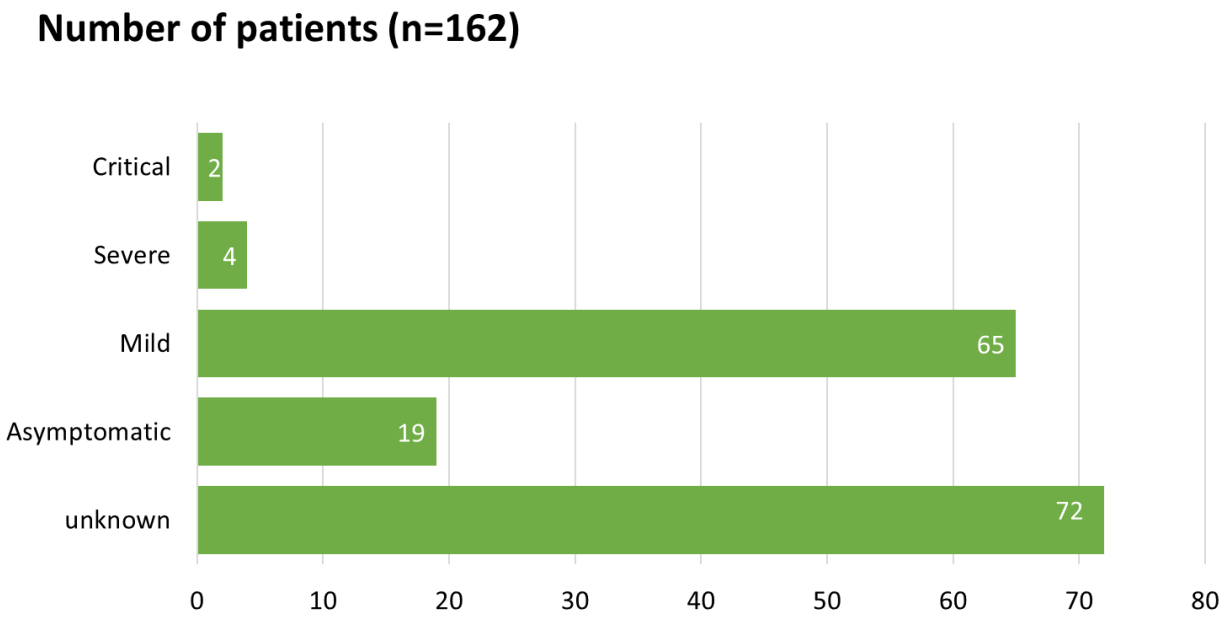
Categories of symptoms:

- Fever / General symptoms: fever, fatigue, headache, arthralgia/myalgia
- Pulmonary symptoms: increased cough, dyspnoea, chest tightness, wheezing, sputum production, haemoptysis
- Other: none of the above
- Asymptomatic: none of the symptoms reported
- Gastrointestinal symptoms: diarrhoea, vomiting/nausea, abdominal pain
- Respiratory failure: respiratory failure

Individual symptoms



COVID-19 severity



Mild: Patients without pneumonia or cases of mild pneumonia

Severe: Patients who suffered from shortness of breath, respiratory frequency ≥ 30/minute, blood oxygen saturation ≤93%, PaO2/FiO2 ratio <300, and/or lung infiltrates >50% within 24–48 hour

Critical: Patients who suffered respiratory failure, septic shock, and/or multiple organ dysfunction or failure.

Source: http://www.ourphn.org.au/wp-content/uploads/20200225-Article-COVID-19.pdf

COVID-19 treatment

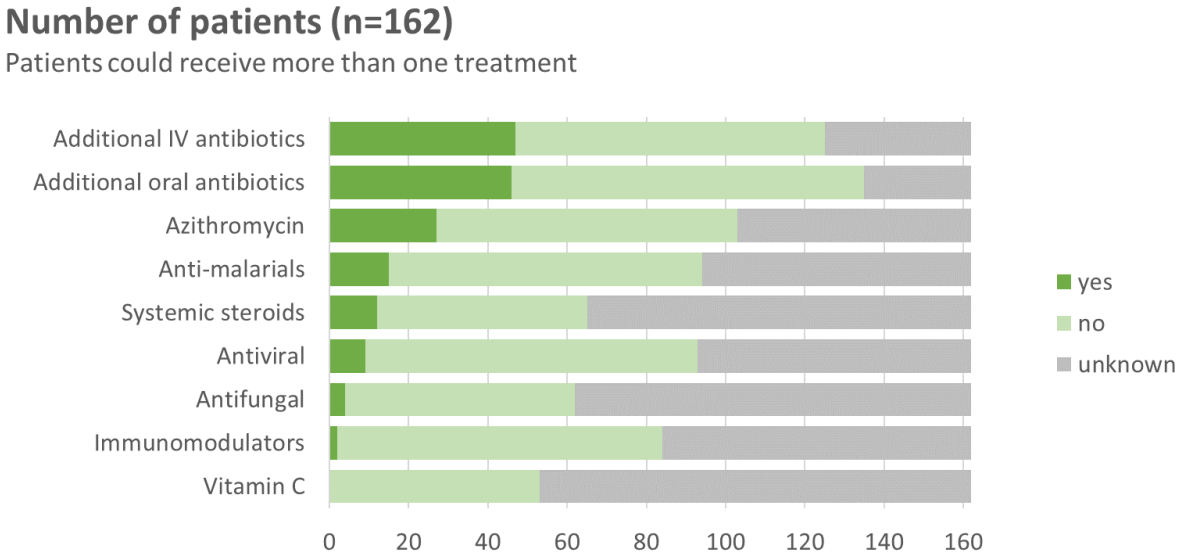
Place of care

66 patients
were hospitalised

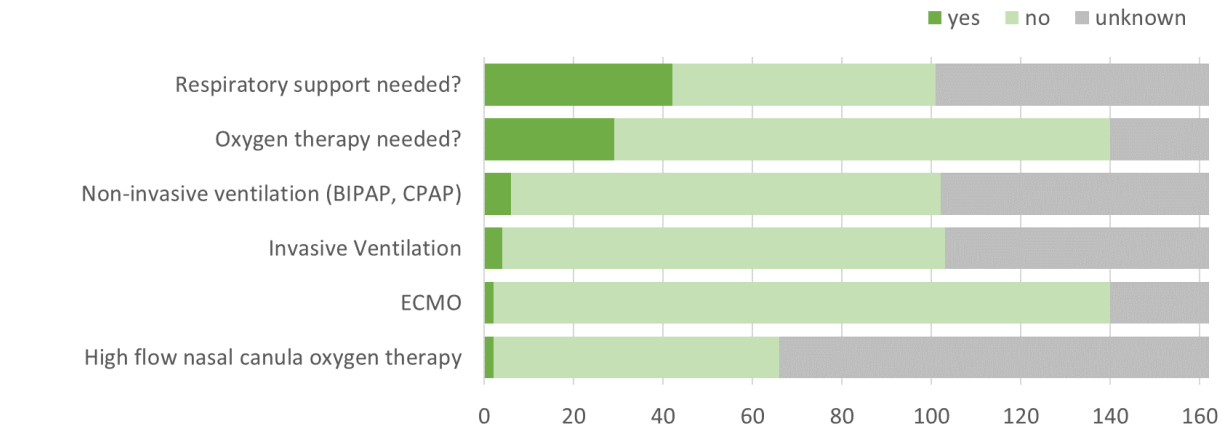
11 hospitalised patients
needed ICU care

COVID-19 treatment

Pharmacological treatment



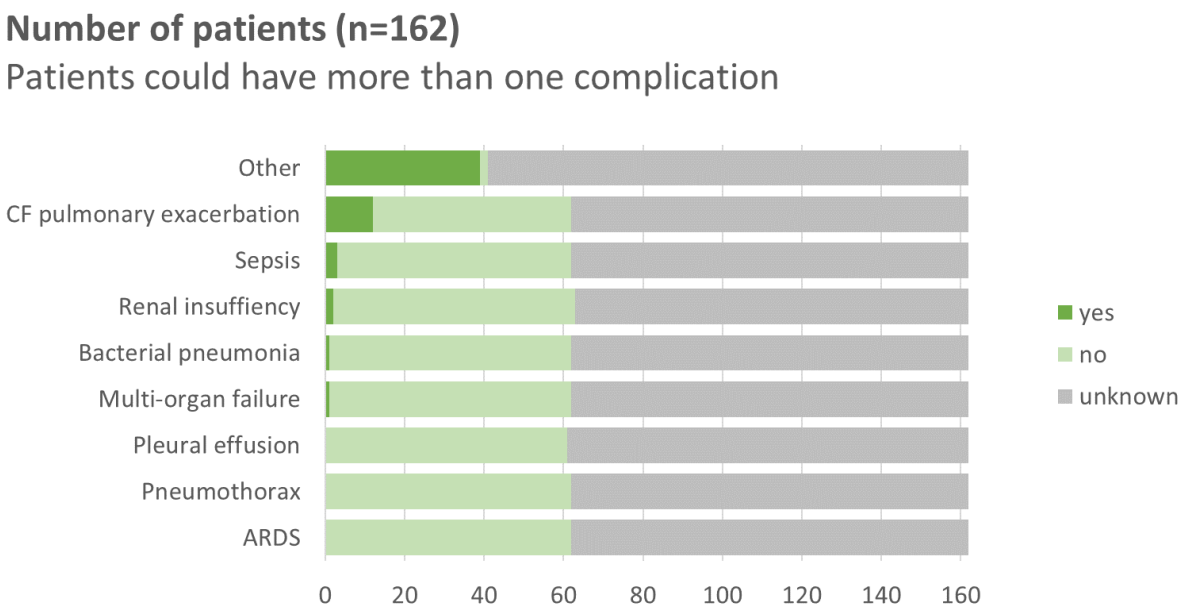
Oxygen and respiratory support



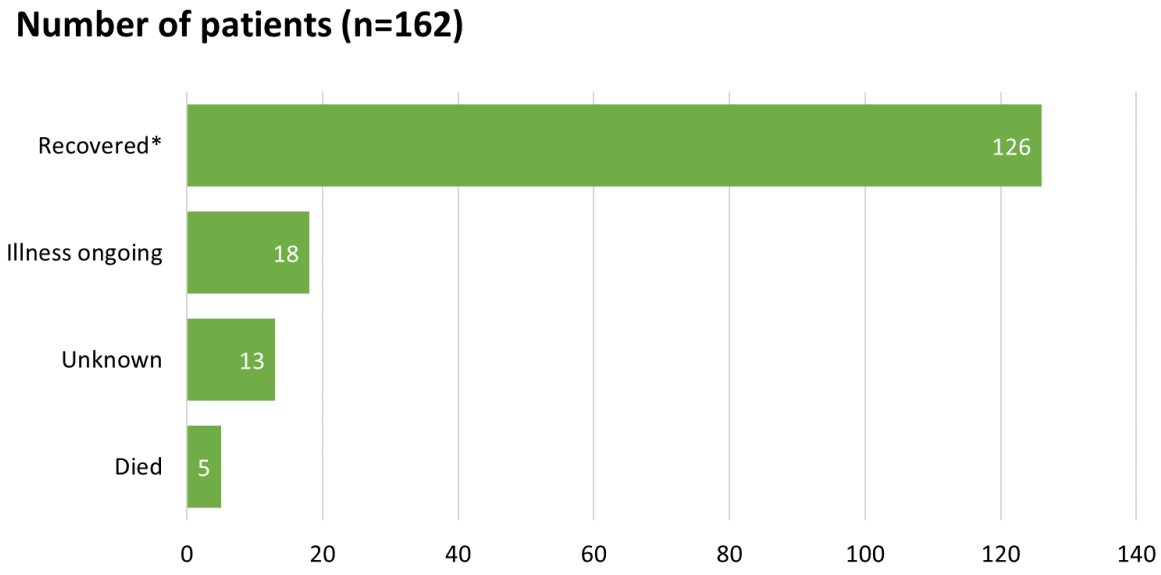
Abbreviations: BIPAP = bi-level positive airway pressure, CPAP = continuous positive airway pressure, ECMO = extra corporeal membrane oxygenation

* In certain cases, patients can have more than one type of respiratory support (e.g. ECMO and invasive ventilation). Therefore, the numbers of patients who needed each type of respiratory support may exceed the

COVID-19 complications



COVID-19 outcomes



*Includes asymptomatic patients and those discharged alive from hospital

Footnotes and references

For data submitted directly to ECFSPR, the following references were used for computation of ppFEV1.

- Percent predicted FEV_1 was calculated using the calculator http://gligastransfer.org.au/calcs/spiro.html based on the last 3 FEV1 (pre-bronchodilator) measurements before infection with SARS-Cov-2.

Icons are from:

- Home by Kahalap from the Noun Project
- Hospital by Made from the Noun Project
- Medical treatment by visual world from the Noun Project