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 at a later date.

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

Summary (up to 20 August 2020)

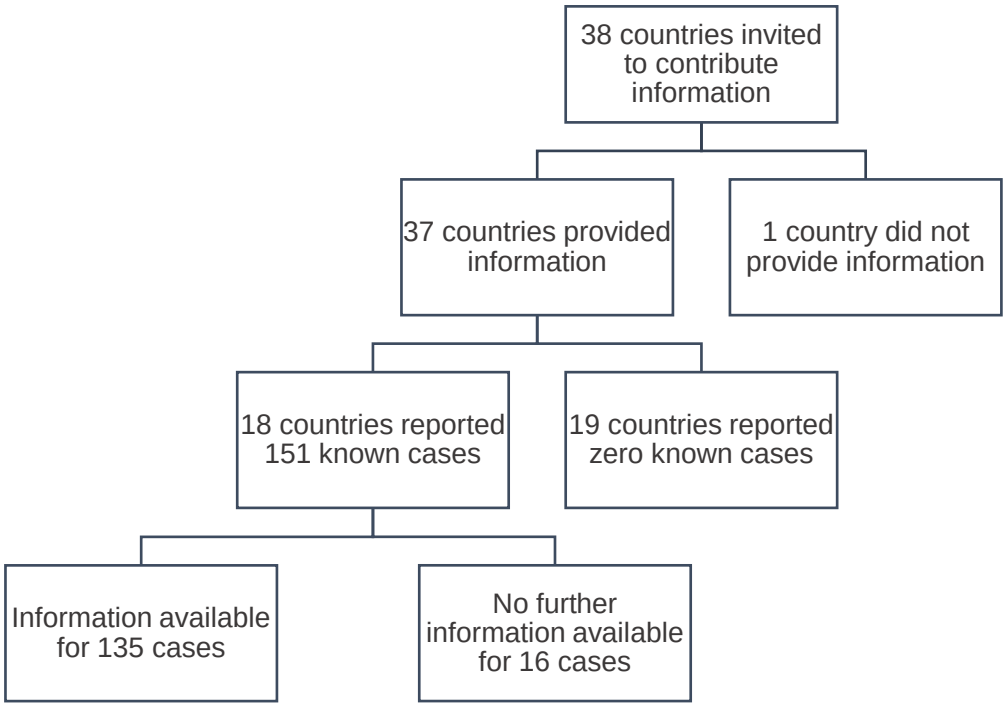
Important update: The ECFSPR database was cleaned in early July to remove patients who did not have a PCR-confirmed diagnosis of infection with SARS-Cov-2. This is because serological antibody tests lack specificity for the SARS-Cov-2 virus compared to other coronaviruses circulating in the population. Aggregate data from national registries may still include patients who have only had an antibody test (without PCR confirmation).

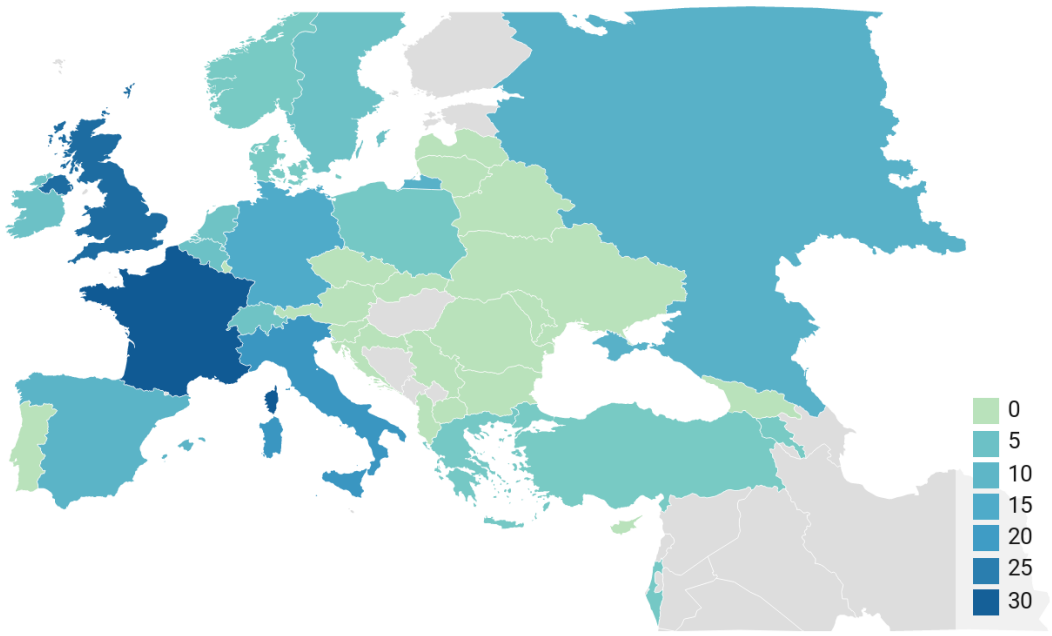
151	135	8	3
People with CF have confirmed COVID-19	Case data available	Needed intensive care	Died

- 5 critical cases
- 3 people with CF and COVID-19 died
- The most common treatments were azithromycin and additional antibiotics (oral and intravenous)

Distribution in Europe

The following flow chart presents the number of countries that reported COVID-19 cases in people with CF by 20 August 2020.



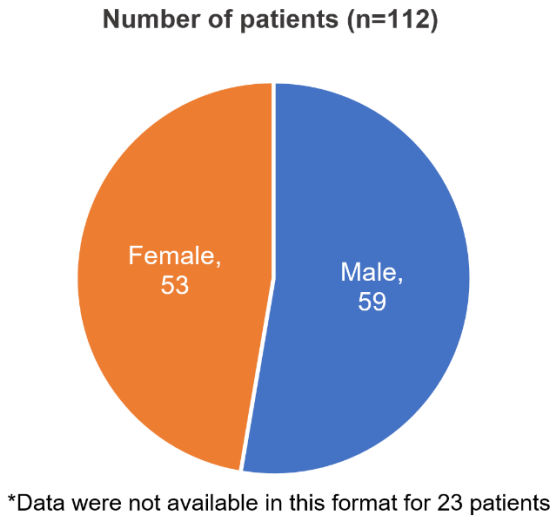


Summary data for the 135 cases with information

The rest of this report presents data for the 135 reported cases with at least partial data. If case reports were incomplete, the missing information has not been considered.

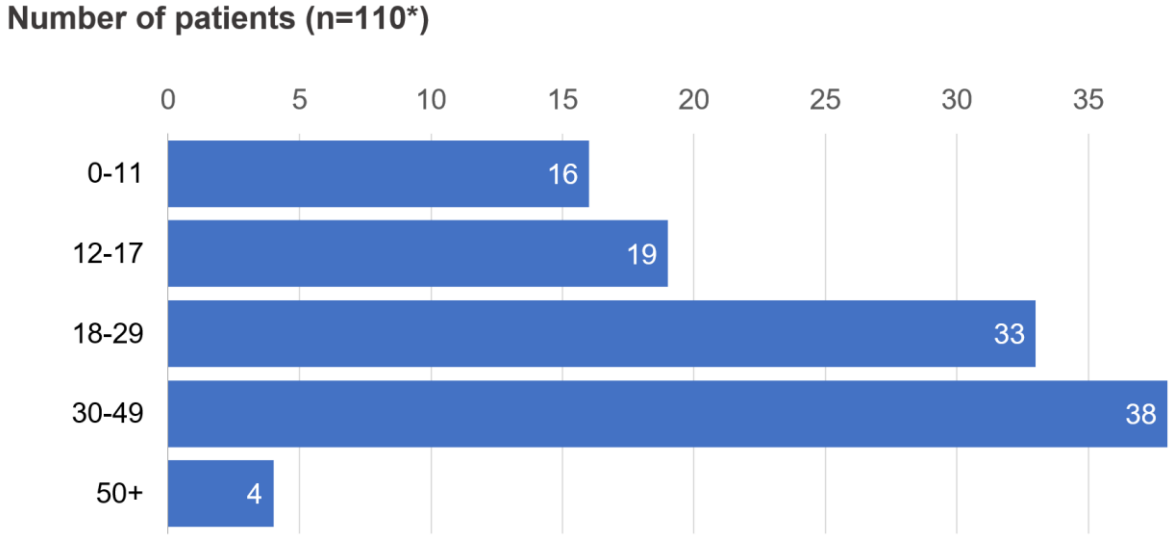
Demographics

Gender



*Data were not available in this format for 23 patients

Age category (years)

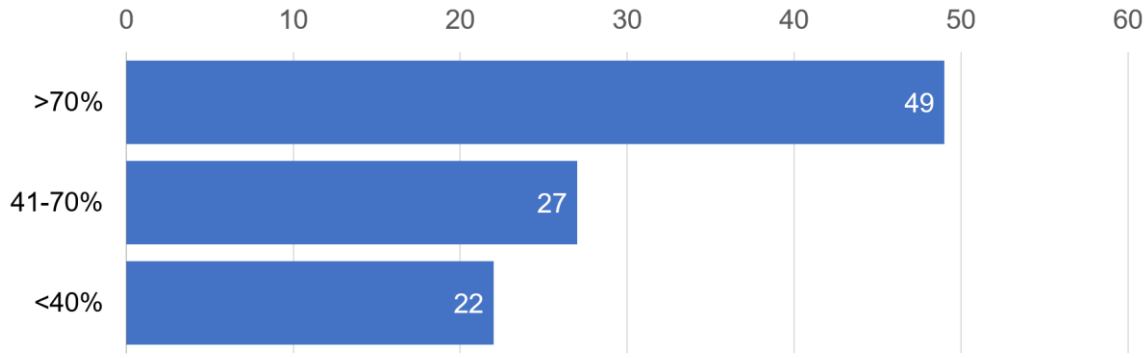


*Data were not available in this format for 25 patients

Cystic fibrosis characteristics

Percent predicted FEV_1, by category

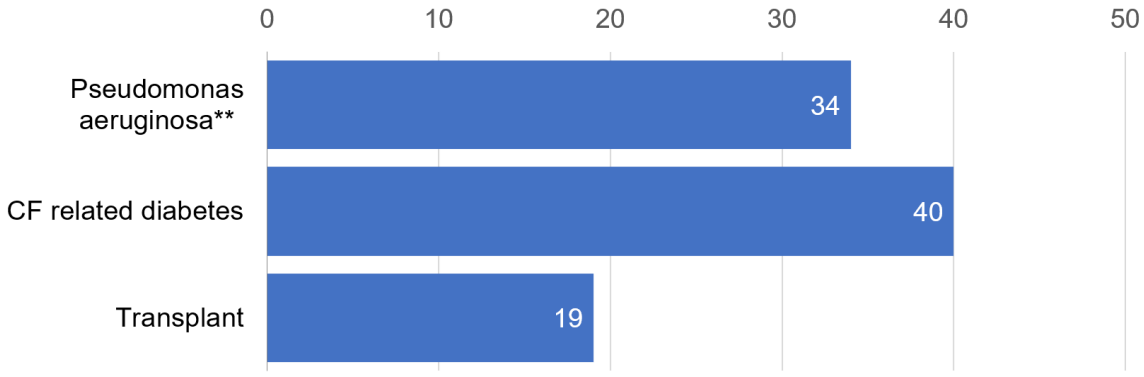
Number of patients (n=98*)



Abbreviation: $ppFEV_1$ = percent predicted forced expiratory volume in one second
*Data were not available in this format for 32 patients. $ppFEV_1$ measurement was not applicable for a further 5 patients.

Other cystic fibrosis characteristics

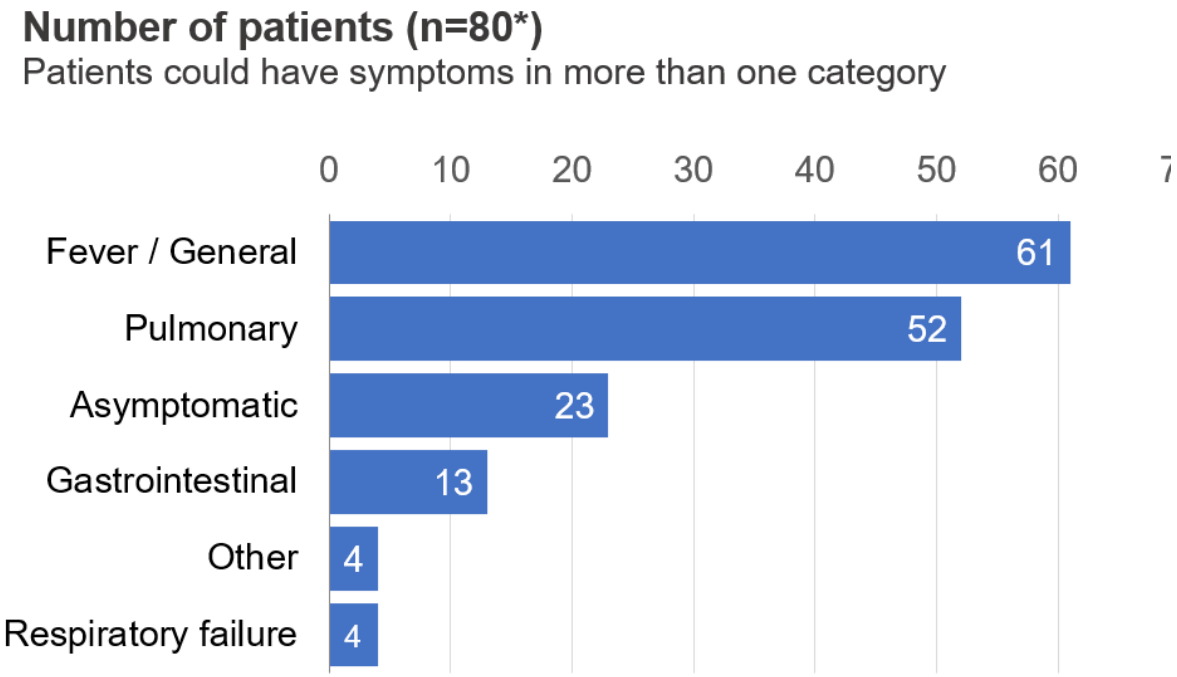
Number of patients (n=114*)
Patients could have between zero and three of these characteristics



*Data were not available in this format for 21 patients
** in the last 12 months (data for *Pseudomonas* infection were not available in this format for a further 29 patients).

COVID-19 symptoms

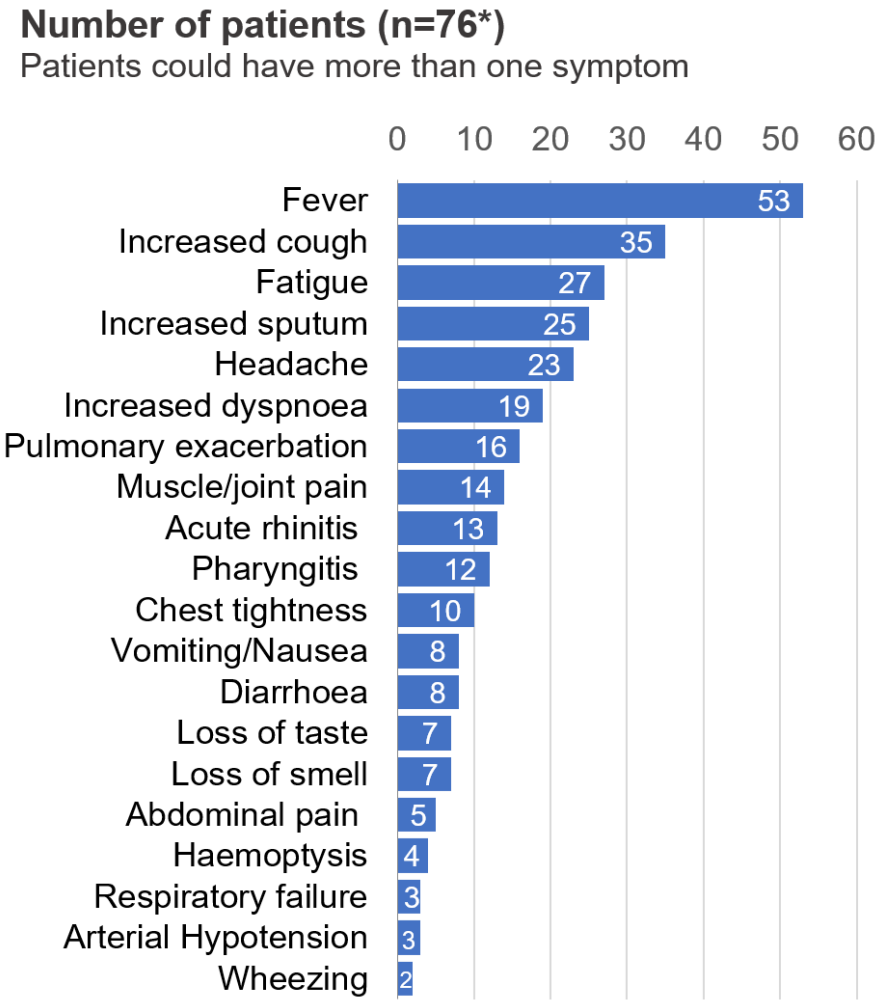
Categories of symptoms



*Data were not available in this format for 55 patients
Patients could have more than one symptom.

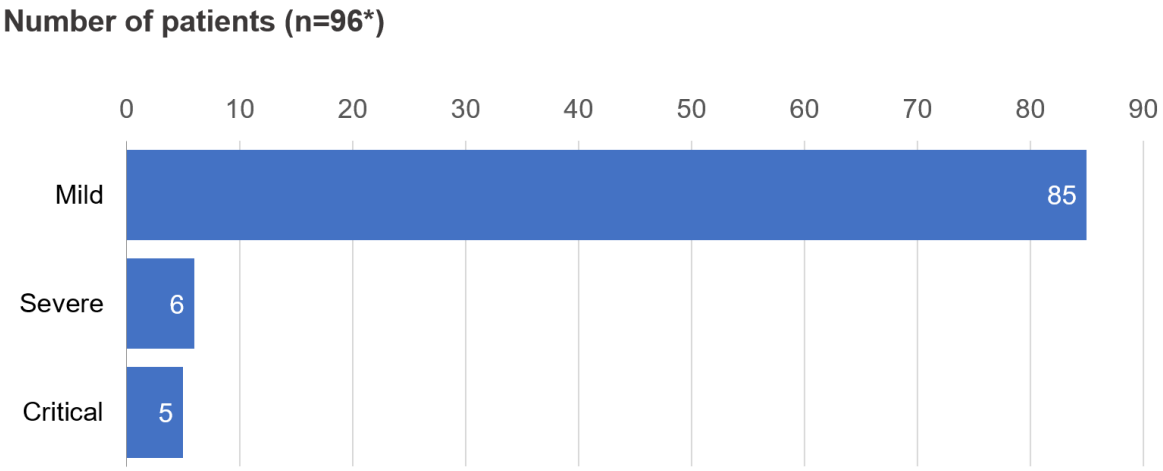
Categories of symptoms:
- Pulmonary symptoms: increased cough, dyspnoea, chest tightness, wheezing
  sputum production, haemoptysis
- Fever / General symptoms: fever, fatigue, headache, arthralgia/myalgia
- Other: none of the above
- Asymptomatic: none of the symptoms reported
- Gastrointestinal symptoms: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

Individual symptoms



*Data were not available in this format for 59 patients

COVID-19 severity



*Data were not available in this format for 39 patients

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 hours

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

COVID-19 treatment

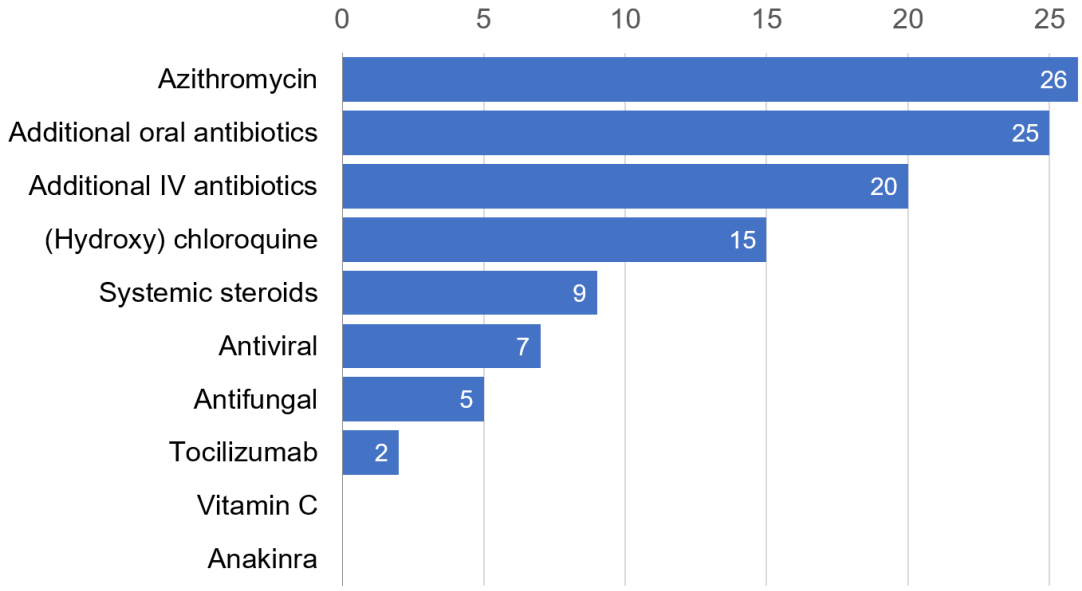
Place of care

70 patients
were hospitalised

8 hospitalised patients
needed ICU care

Pharmacological treatment

Number of patients (n=80*)
Patients could receive more than one treatment



*Data were not available in this format for 55 patients

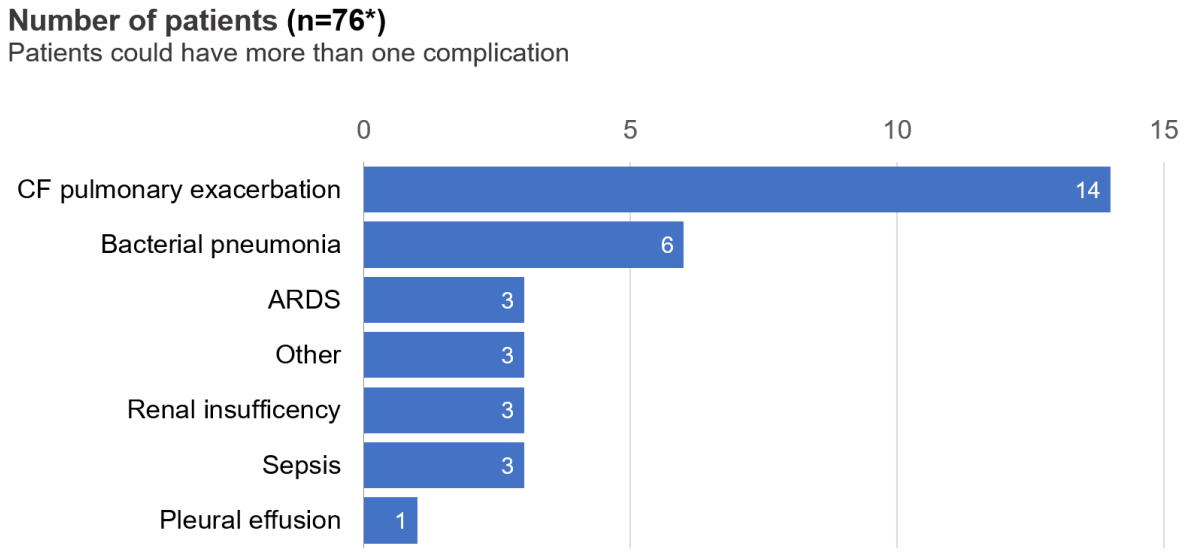
Oxygen and respiratory support

	Number of patients with information N=114
Oxygen therapy needed	28
Respiratory support needed*	7
Non-invasive ventilation (BIPAP, CPAP)	2
High flow nasal canula oxygen therapy	4
Invasive Ventilation	3
ECMO	1

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

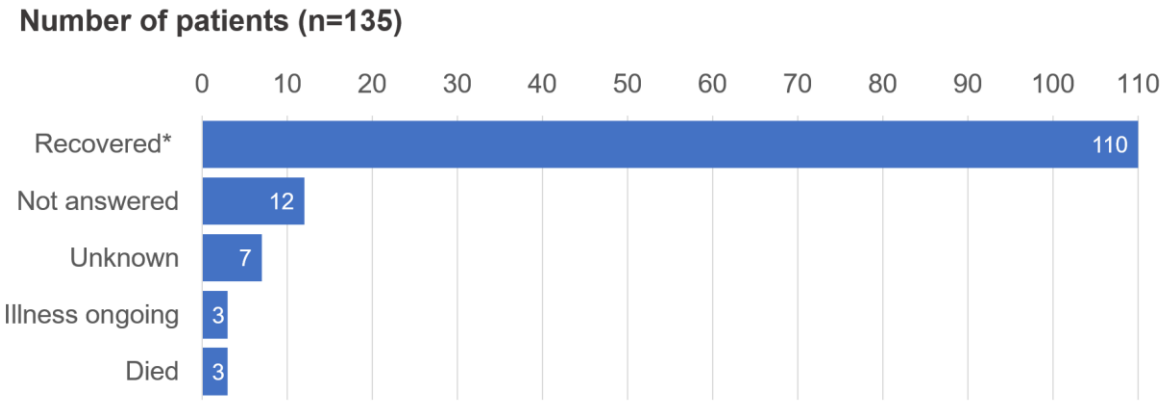
***** In certain cases, patients can have more than one type of respiratory support (e.g. ECMO and invasive ventilation). Therefore the numbers of patients who needed each type of respiratory support may exceed the total number of patients who needed respiratory support.

COVID-19 complications



*Data were not available in this format for 59 patients
ARDS = acute respiratory distress syndrome

COVID-19 outcomes



*or 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