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 PCR-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 13 November 2020)

| 278	197	12	5
People with CF have COVID-19 (including some cases not confirmed by PCR)	PCR-confirmed cases with 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 13 November 2020.

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          ┌─────────────────────┐
          │ 38 countries invited│
          │   to contribute     │
          │   information       │
          └──────────┬──────────┘
                     │
          ┌──────────┴──────────┐
          │   38 countries      │
          │   provided          │
          │   information       │
          └──────────┬──────────┘
            ┌────────┴─────────┐
   ┌────────┴───────┐   ┌──────┴─────────┐
   │  20 countries  │   │  18 countries  │
   │  reported 278  │   │  reported zero │
   │  known cases*  │   │  known cases   │
   └────────┬───────┘   └────────────────┘
   ┌────────┴───────┐
   │  Information   │
   │  available for 197│
   │  PCR-confirmed │
   │  cases         │
   └────────────────┘
```

*including some cases not confirmed by PCR
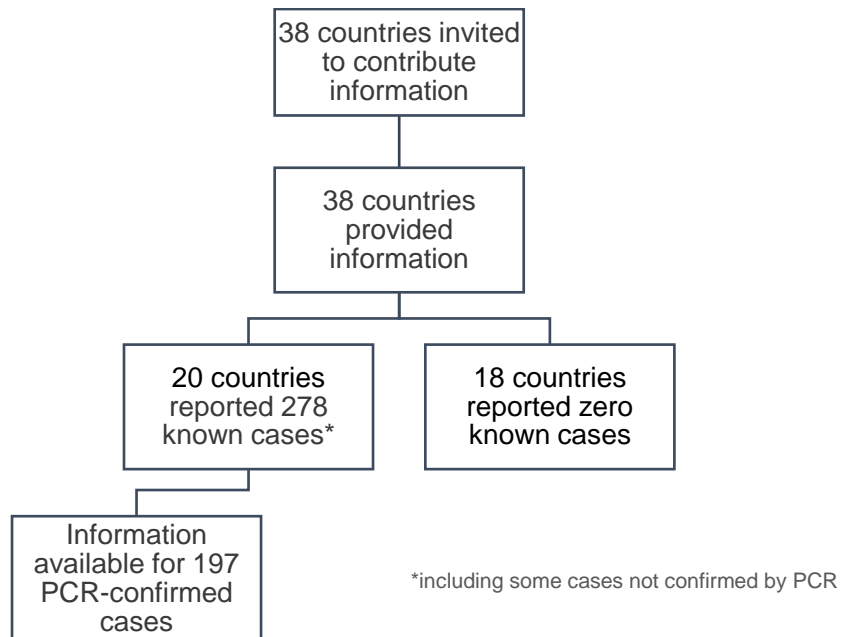
COVID-19 in people with CF

Data up to 13 November 2020

| 0 | 25 | 50 |
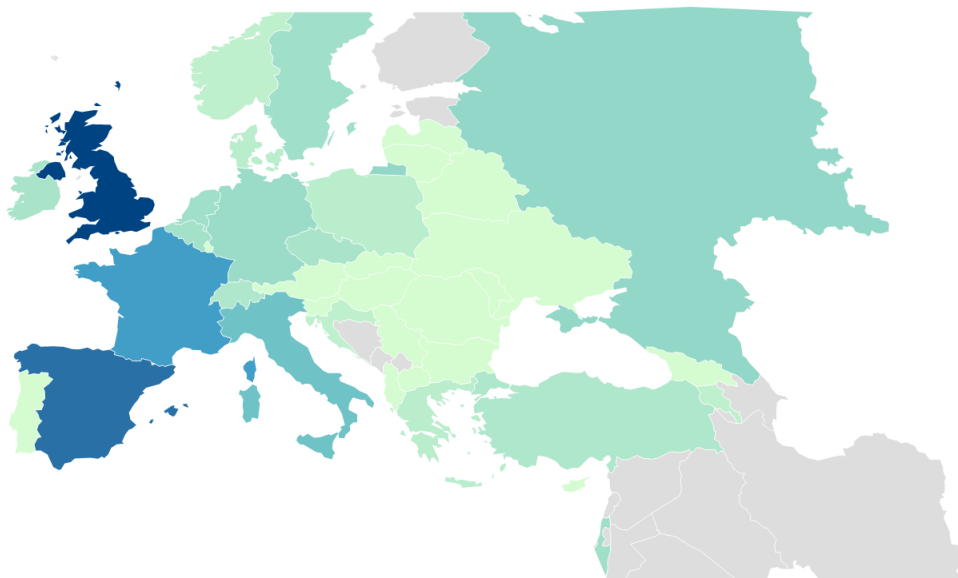
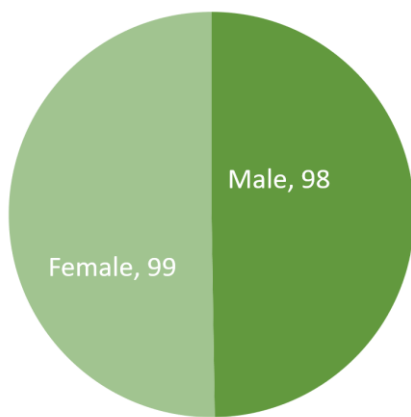*Countries in grey did not submit any information*

Created with Datawrapper

Summary data for the 197 cases with information

The rest of this report presents data for the 197 reported cases with at least partial data. If case reports were incomplete, the missing information has not been considered.
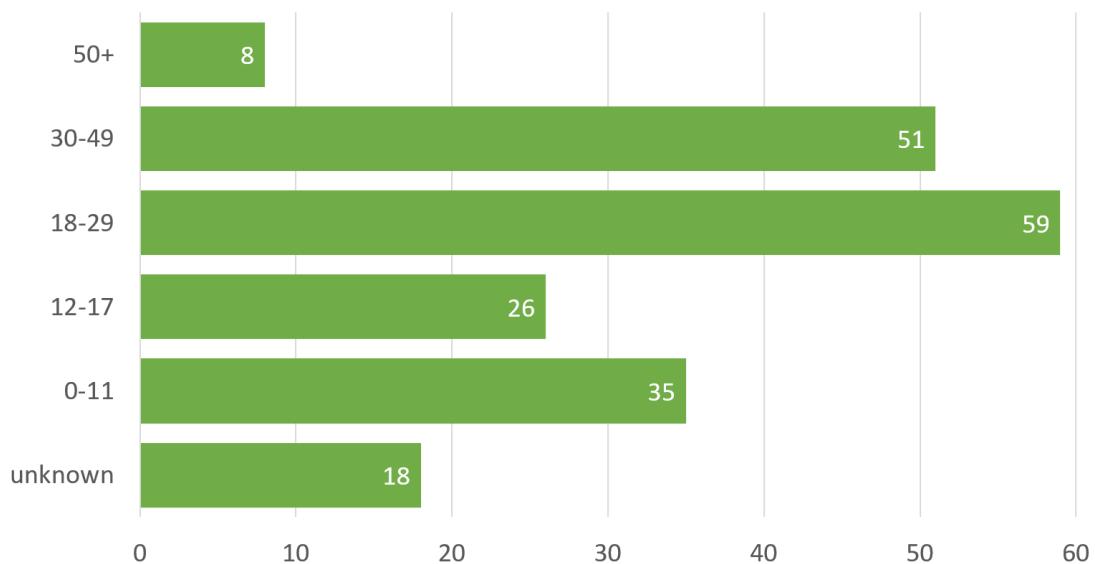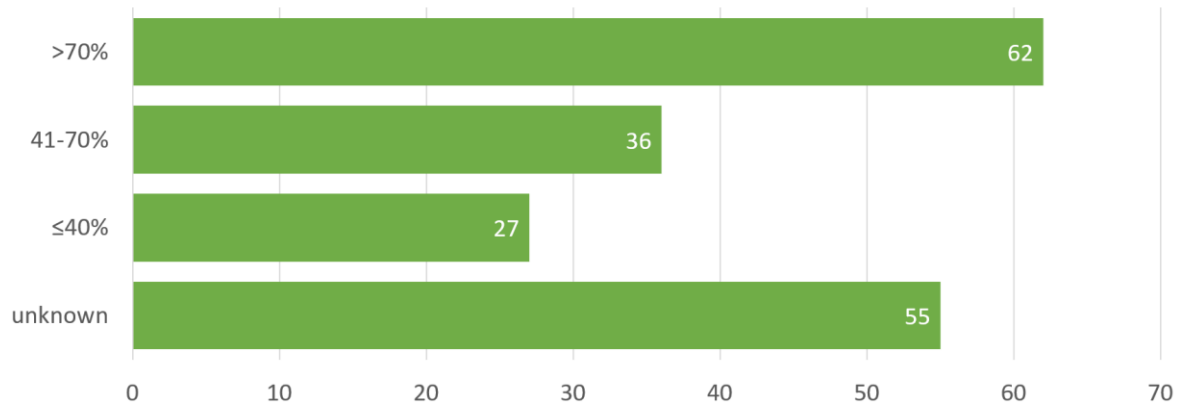
Demographics

Gender

Male, 98
Female, 99

Age category (years)

Number of patients (n=197)

Age category	Number
50+	8
30-49	51
18-29	59
12-17	26
0-11	35
unknown	18

Cystic fibrosis characteristics

Percent predicted FEV$_1$, by category
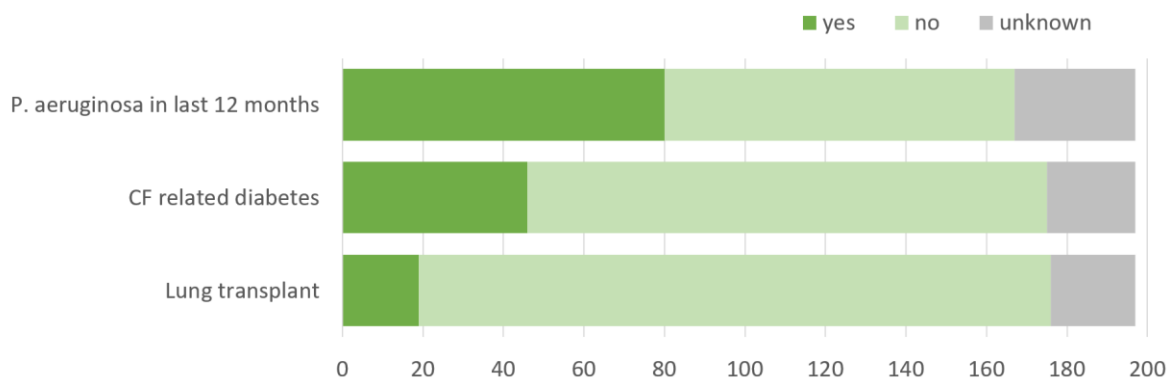
Number of patients (n=180*)

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=197)
Patients could have between 0 and 3 of these characteristics
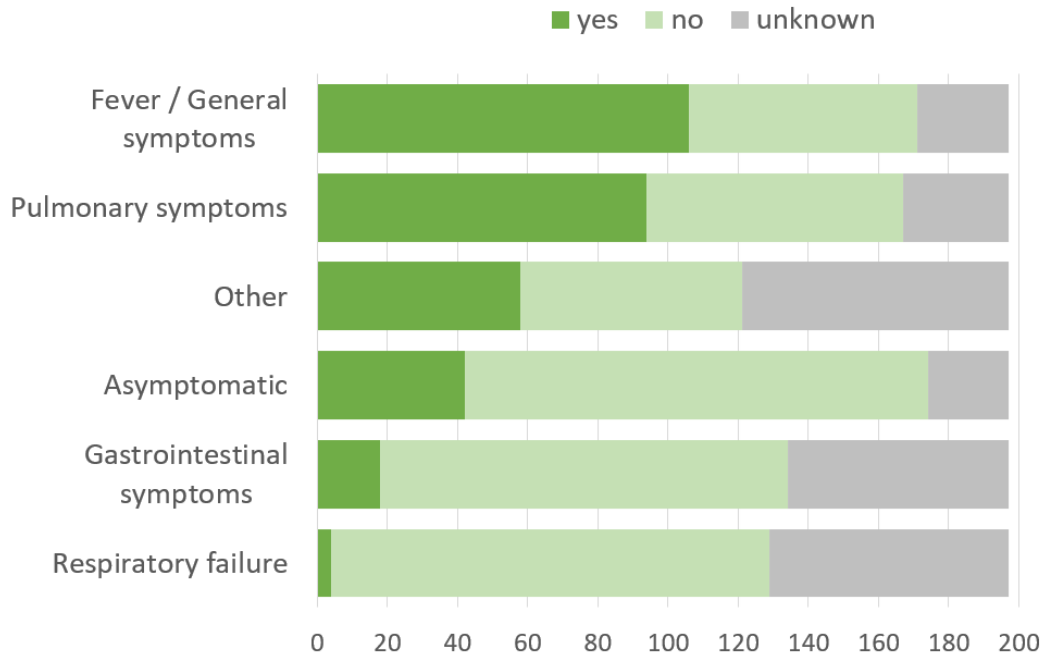
COVID-19 symptoms

Categories of symptoms

Number of patients (n=197)

Patients could have symptoms in >1 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
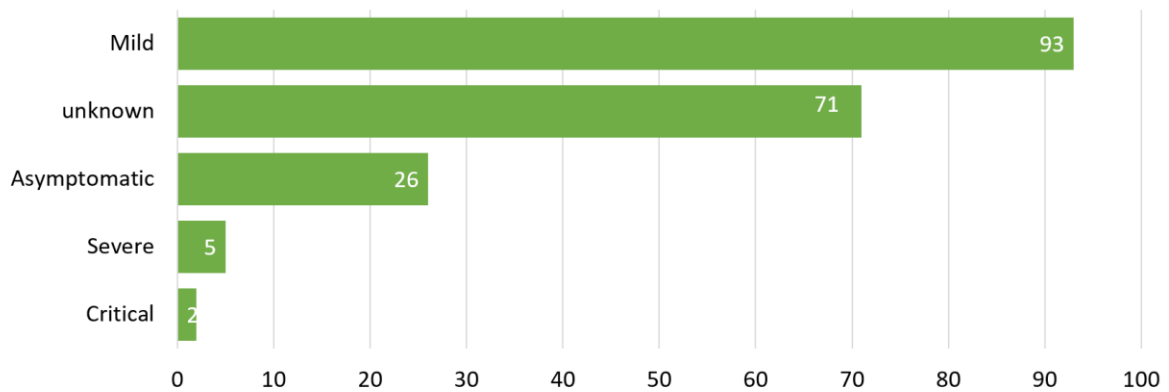 - Respiratory failure: respiratory failure

Number of patients (n=197)
Patients could have more than 1 symptom
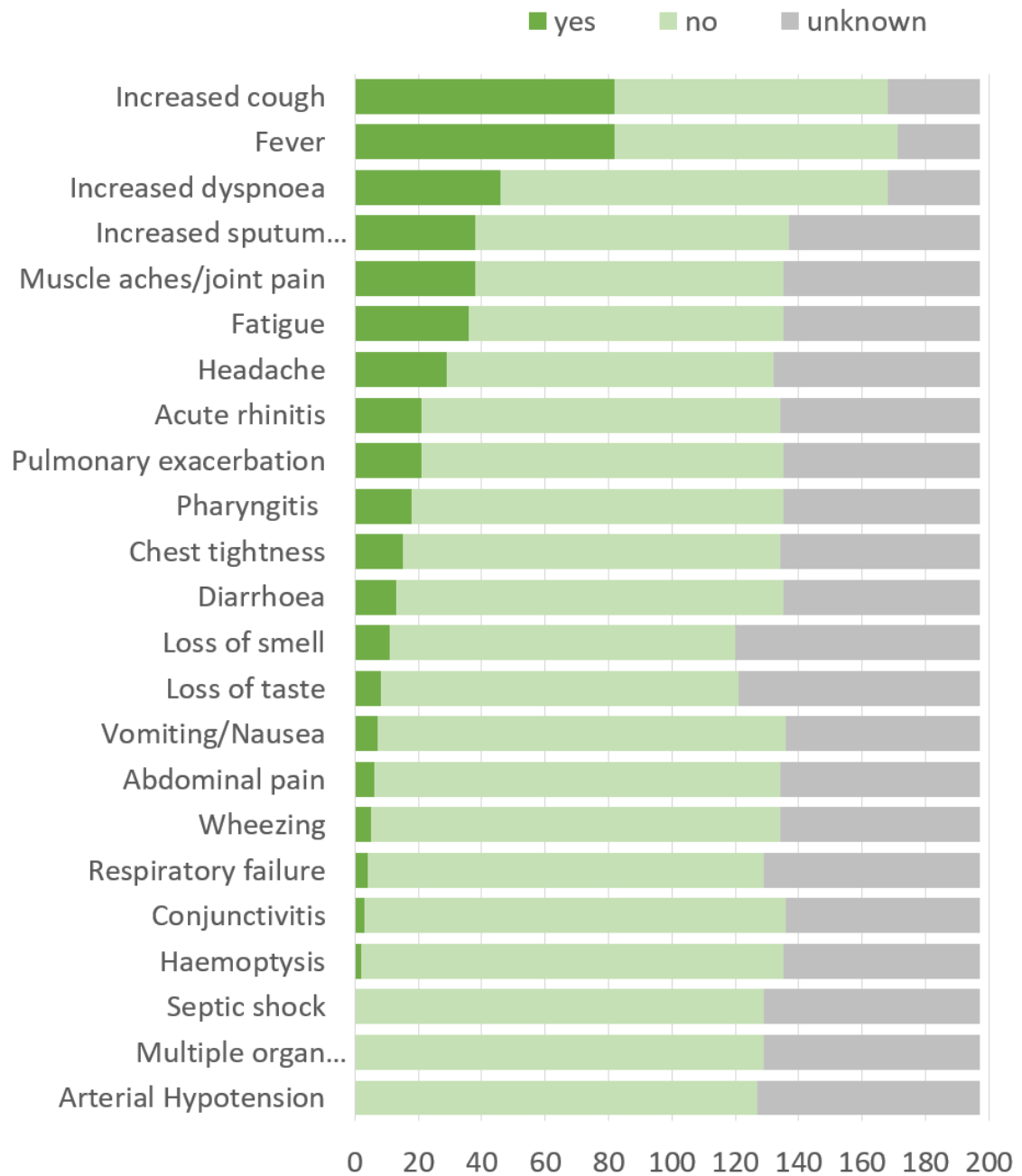
COVID-19 severity

Number of patients (n=197)

Severity	Number
Mild	93
unknown	71
Asymptomatic	26
Severe	5
Critical	2

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.

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

COVID-19 treatment

Place of care

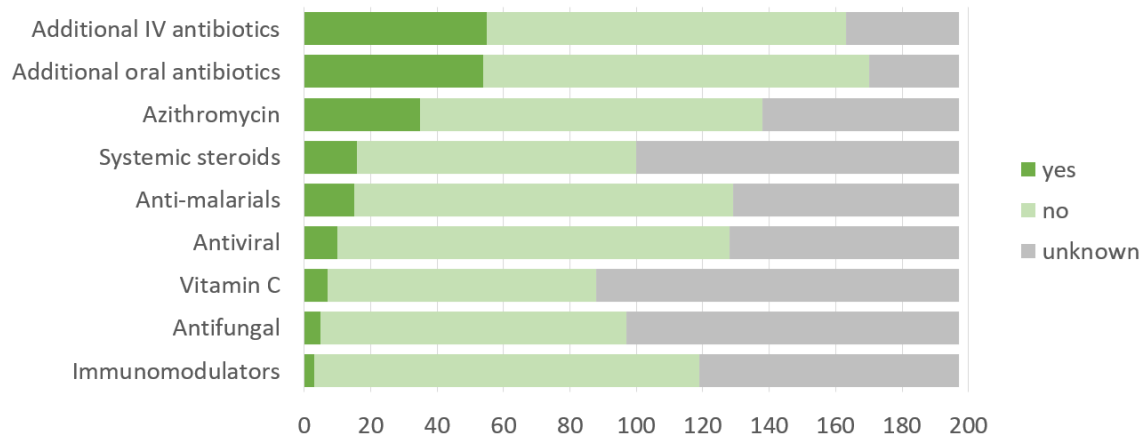### 72 patients
were hospitalised

12 hospitalised patients
needed ICU care

COVID-19 treatment
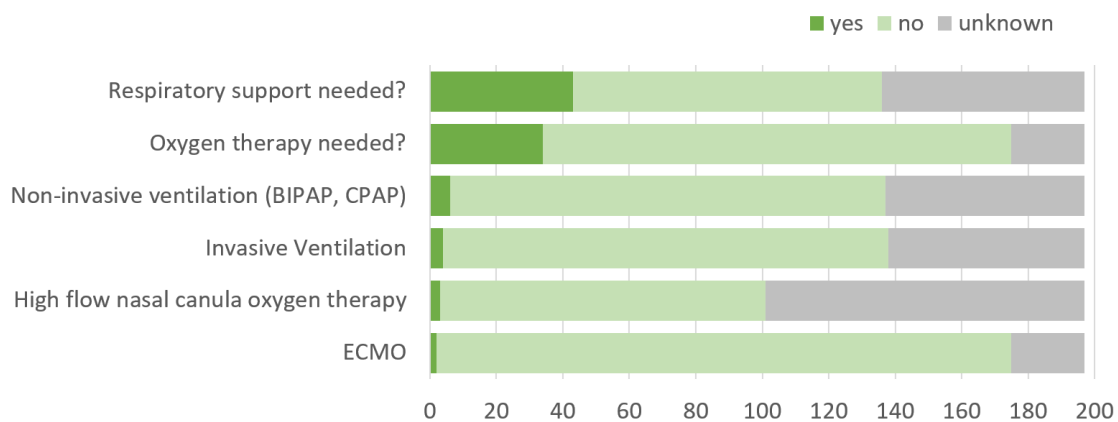
Pharmacological treatment

Number of patients (n=197)

Patients could receive more than one treatment

Oxygen and respiratory support

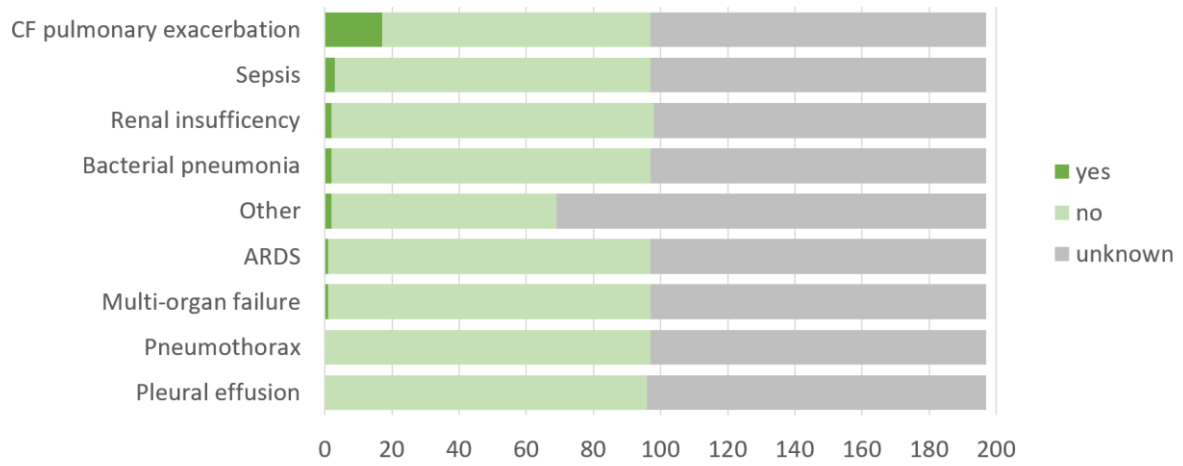### Number of patients (n=197)

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.
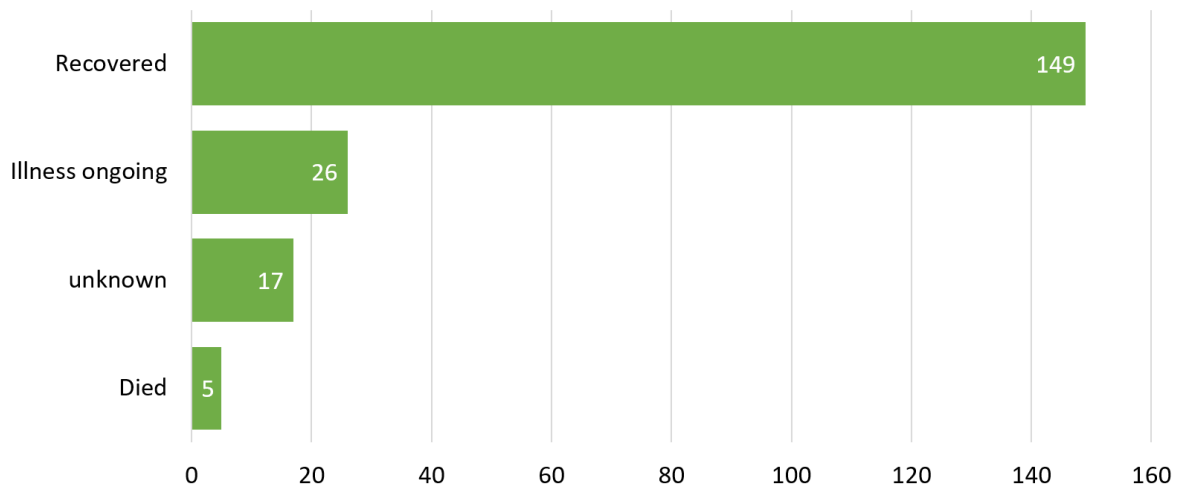
COVID-19 complications

Number of patients (n=197)
Patients could have more than one complication

Legend: yes / no / unknown

Categories (top to bottom): CF pulmonary exacerbation, Sepsis, Renal insufficency, Bacterial pneumonia, Other, ARDS, Multi-organ failure, Pneumothorax, Pleural effusion

COVID-19 outcomes

Number of patients (n=197)

Outcome	Number
Recovered	149
Illness ongoing	26
unknown	17
Died	5

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