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 May 2020)

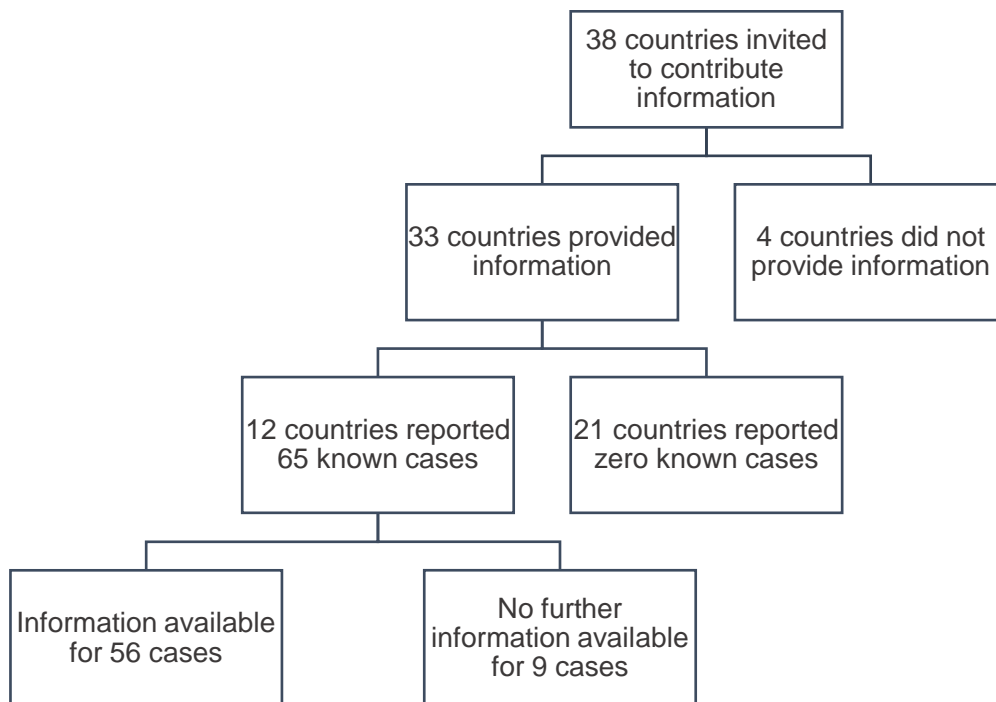| 65	56	6	3
People with CF have confirmed COVID-19	Case data available	Needed intensive care	Died

- 3 critical cases
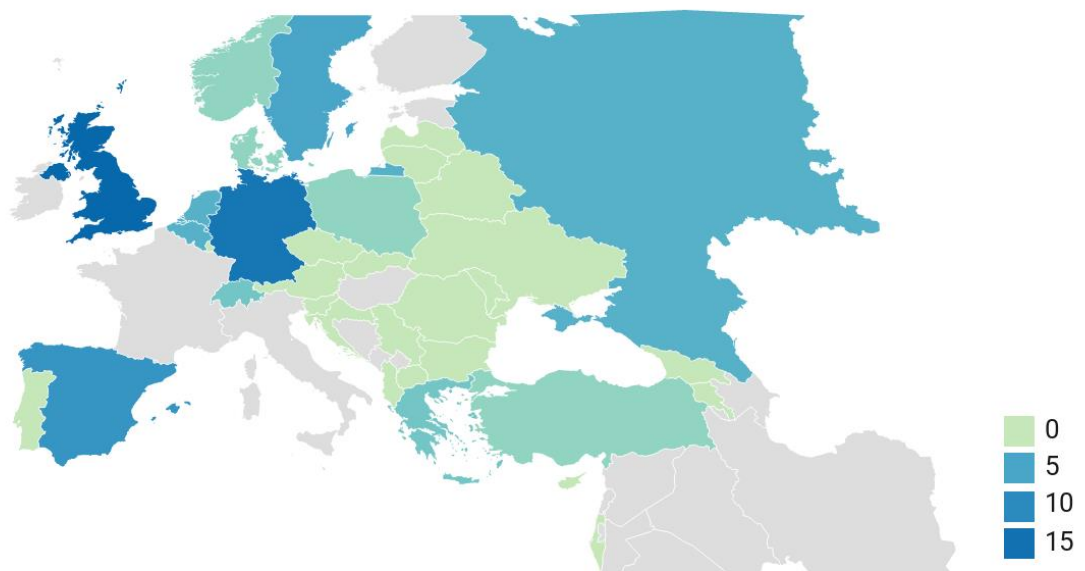- Three person with CF and COVID-19 died
- A range of therapies used

Distribution in Europe

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

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              ┌──────────────────────┐
              │  38 countries invited │
              │    to contribute      │
              │    information        │
              └──────────────────────┘
                   ┌──────┴──────┐
        ┌────────────────────┐  ┌────────────────────┐
        │ 33 countries provided│  │ 4 countries did not │
        │    information       │  │ provide information │
        └────────────────────┘  └────────────────────┘
             ┌──────┴──────┐
   ┌────────────────────┐  ┌────────────────────┐
   │ 12 countries reported│  │ 21 countries reported│
   │   65 known cases     │  │   zero known cases   │
   └────────────────────┘  └────────────────────┘
        ┌──────┴──────┐
┌────────────────┐  ┌────────────────────┐
│ Information     │  │   No further        │
│ available       │  │ information available│
│ for 56 cases    │  │   for 9 cases        │
└────────────────┘  └────────────────────┘
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COVID-19 in people with CF

Data up to 20 May 2020

Legend: 0, 5, 10, 15

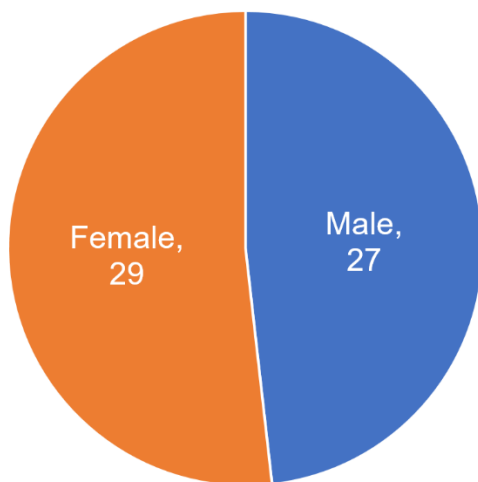*Countries in grey did not submit any information*

Created with Datawrapper

Summary data for the 56 cases with information

The rest of this report presents data for the 56 reported cases. If case reports were incomplete, the missing information has not been considered.
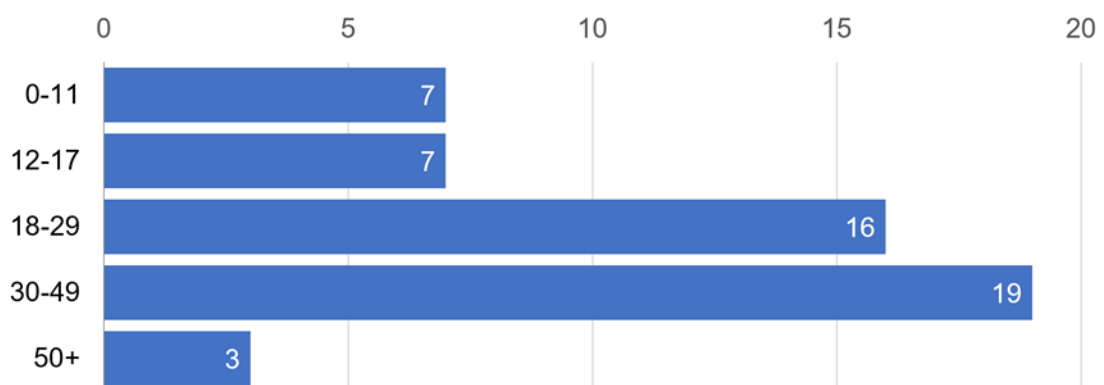
Demographics

Gender

Number of patients (n=56)

Female, 29

Male, 27

Age category (years)

Number of patients (n=52*)

Age category	Number
0-11	7
12-17	7
18-29	16
30-49	19
50+	3

*Data were not available in this format for 4 patients

Cystic fibrosis characteristics

Percent predicted FEV$_1$, by category
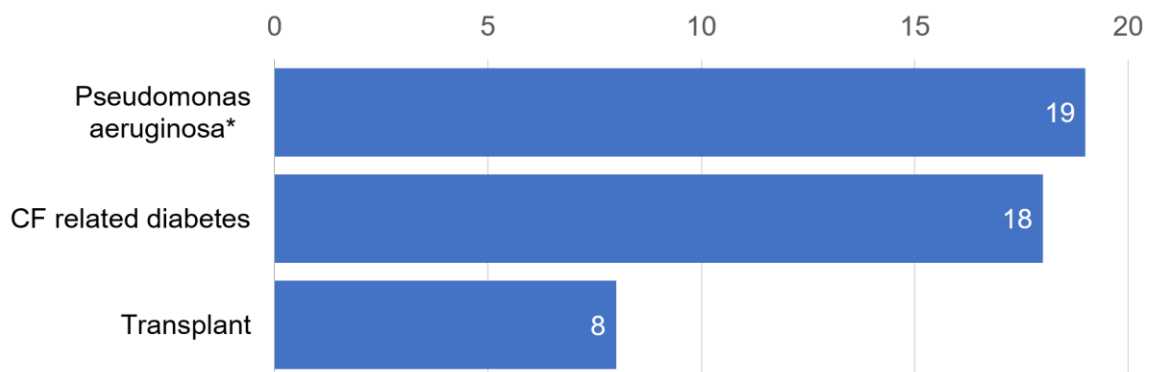
Number of patients (n=56)
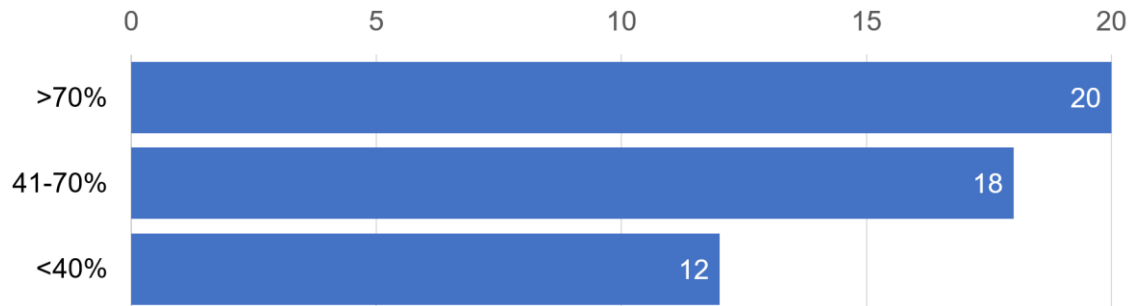
Abbreviation: ppFEV$_1$ = percent predicted forced expiratory volume in one second

Other cystic fibrosis characteristics

Number of patients (n=56)
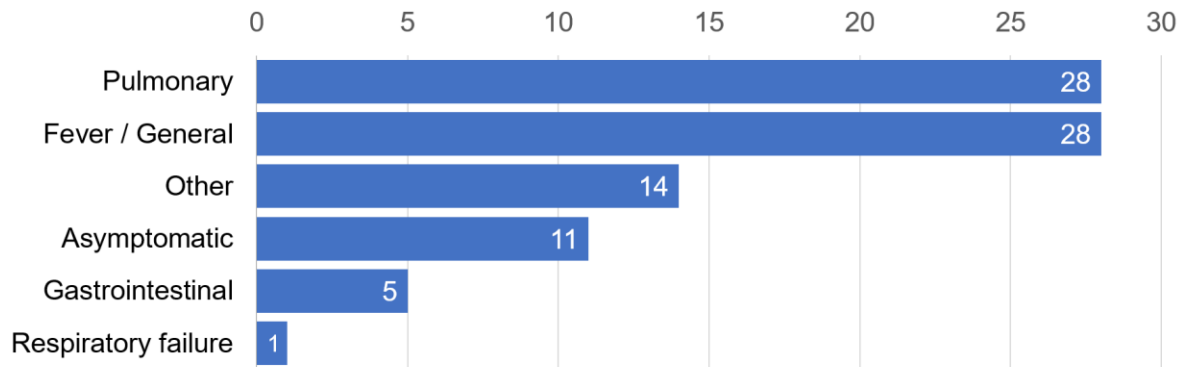Patients could have more than one characteristic

* in the last 12 months (data for *Pseudomonas* infection were not available in this format for 18 patients).

COVID-19 symptoms

Categories of symptoms

Number of patients (n=34*)
Patients could have symptoms in more than one category

Category	Value
Pulmonary	28
Fever / General	28
Other	14
Asymptomatic	11
Gastrointestinal	5
Respiratory failure	1

*Data were not available in this format for 22 patients
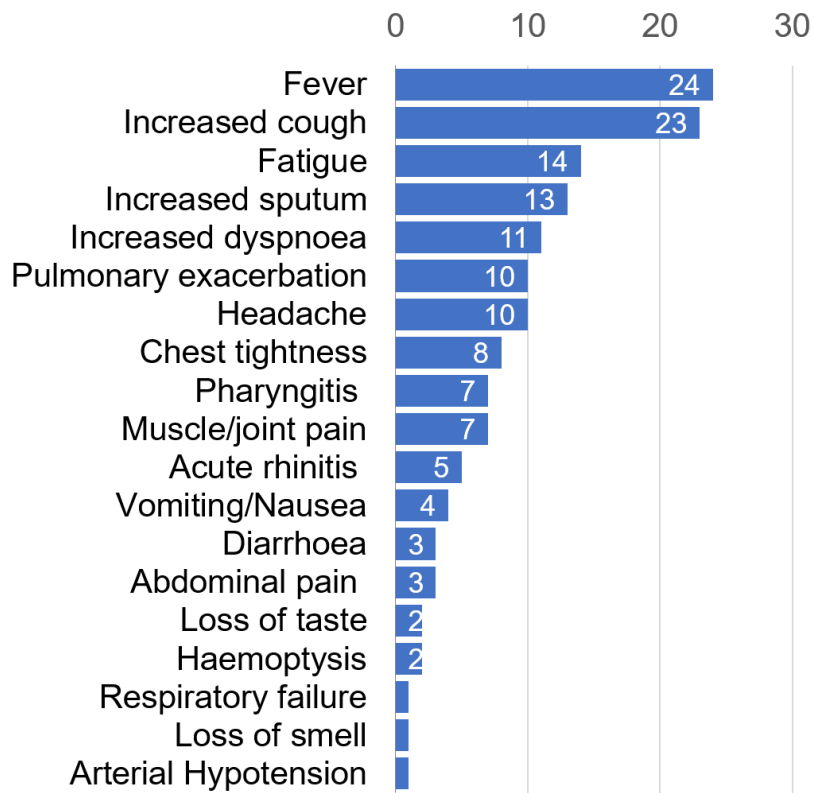Patients could have more than one symptom.

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
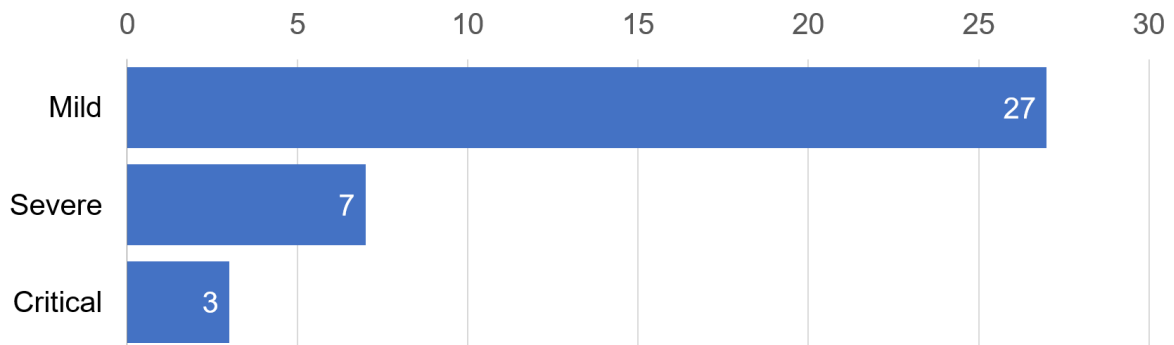
Number of patients (n=34*)

Patients could have more than one symptom

*Data were not available in this format for 22 patients

COVID-19 severity

Number of patients (n=37*)

*Data were not available in this format for 19 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

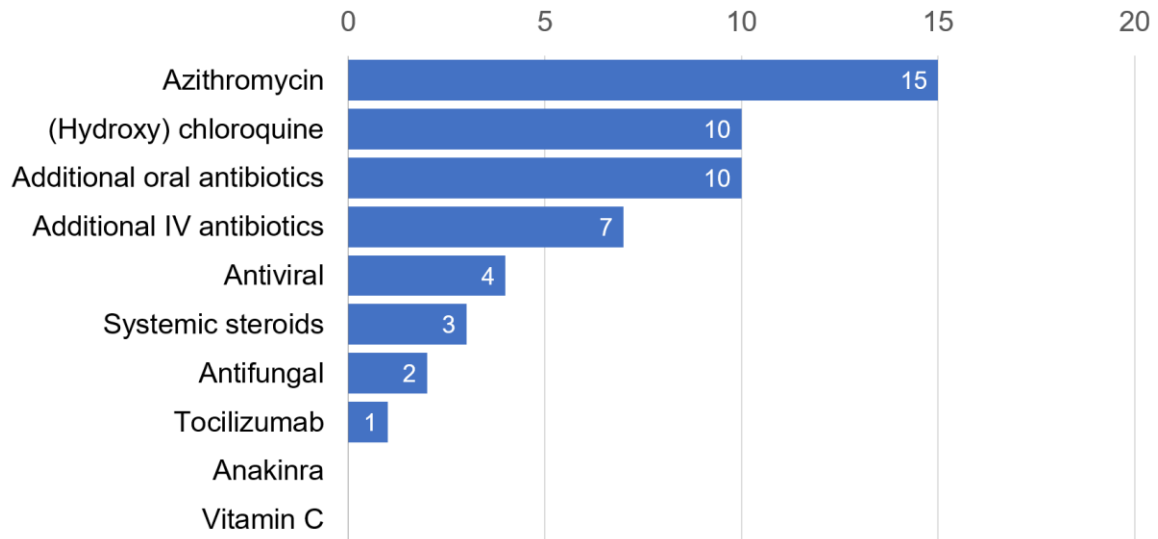## Place of care

35 patients
were hospitalised

6 hospitalised patients
needed ICU care

Pharmacological treatment

Number of patients (n=34*)
Patients could receive more than one treatment

Treatment	Number
Azithromycin	15
(Hydroxy) chloroquine	10
Additional oral antibiotics	10
Additional IV antibiotics	7
Antiviral	4
Systemic steroids	3
Antifungal	2
Tocilizumab	1
Anakinra	
Vitamin C	

*Data were not available in this format for 22 patients

Oxygen and respiratory support

	Number of patients
Oxygen therapy needed	16
Respiratory support needed*	2
Non-invasive ventilation (BIPAP, CPAP)	1
High flow nasal canula oxygen therapy	0
Invasive Ventilation	1
ECMO	1

Abbreviations: BIPAP = bi-level positive airway pressure, CPAP = continuous positive airway pressure, ECMO = extra corporeal membrane oxygenation
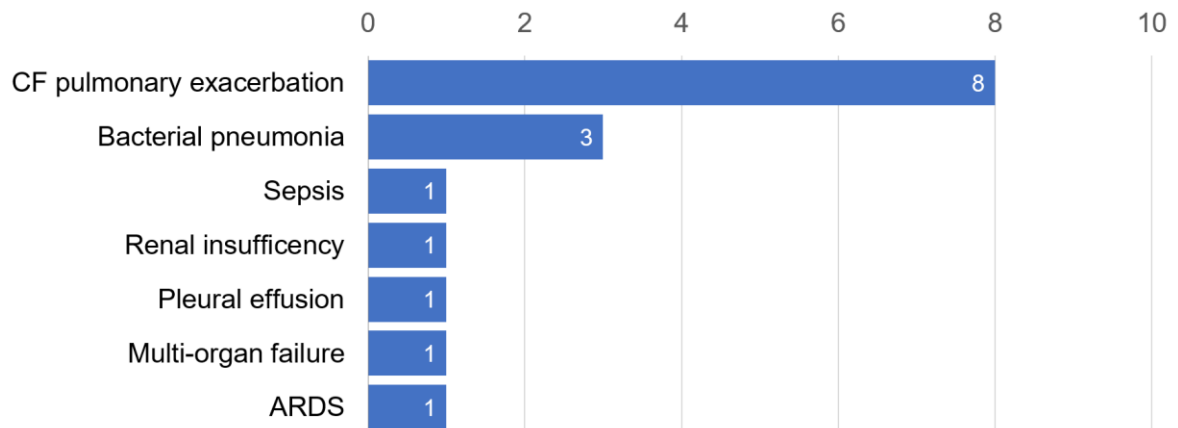
* In certain cases, patients can have more than one type of respiratory support (e.g. ECMO and invasive ventilation). Therefore the numbers of patients who needed each type of respiratory support may exceed the total number of patients who needed respiratory support.

COVID-19 complications

Number of patients (n=34*)
Patients could have more than one complication

Complication	Value
CF pulmonary exacerbation	8
Bacterial pneumonia	3
Sepsis	1
Renal insufficency	1
Pleural effusion	1
Multi-organ failure	1
ARDS	1

*Data were not available in this format for 22 patients
ARDS = acute respiratory distress syndrome

COVID-19 outcomes

Number of patients (n=56)

Outcome	Value
Recovered*	32
Illness ongoing	13
Unknown	8
Died	3
Not answered	
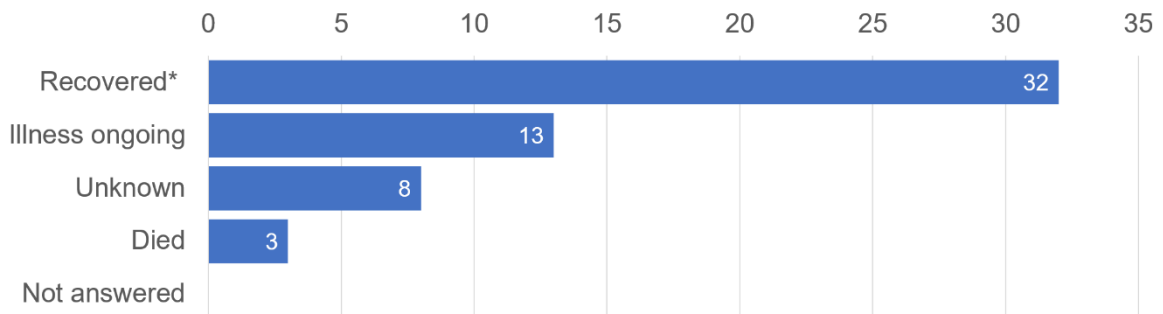
*or discharged alive from hospital

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