

# PH Care COVID Survey: An International Patient Survey on the Care for Pulmonary Hypertension Patients during the Early Phase of the COVID-19 Pandemic

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Acknowledgment. This survey was supported by: PHA Europe, the European Reference Network for rare lung diseases (ERN-LUNG), the European Respiratory Society (ERS) Assembly 13 on Pulmonary Vascular Diseases, the ERS Clinical Research Collaboration PHAROS, the European Lung Foundation (ELF) and the European Society of Cardiology (ESC) Working Group on Pulmonary Circulation & Right Ventricular Function.

## Background and Patient survey

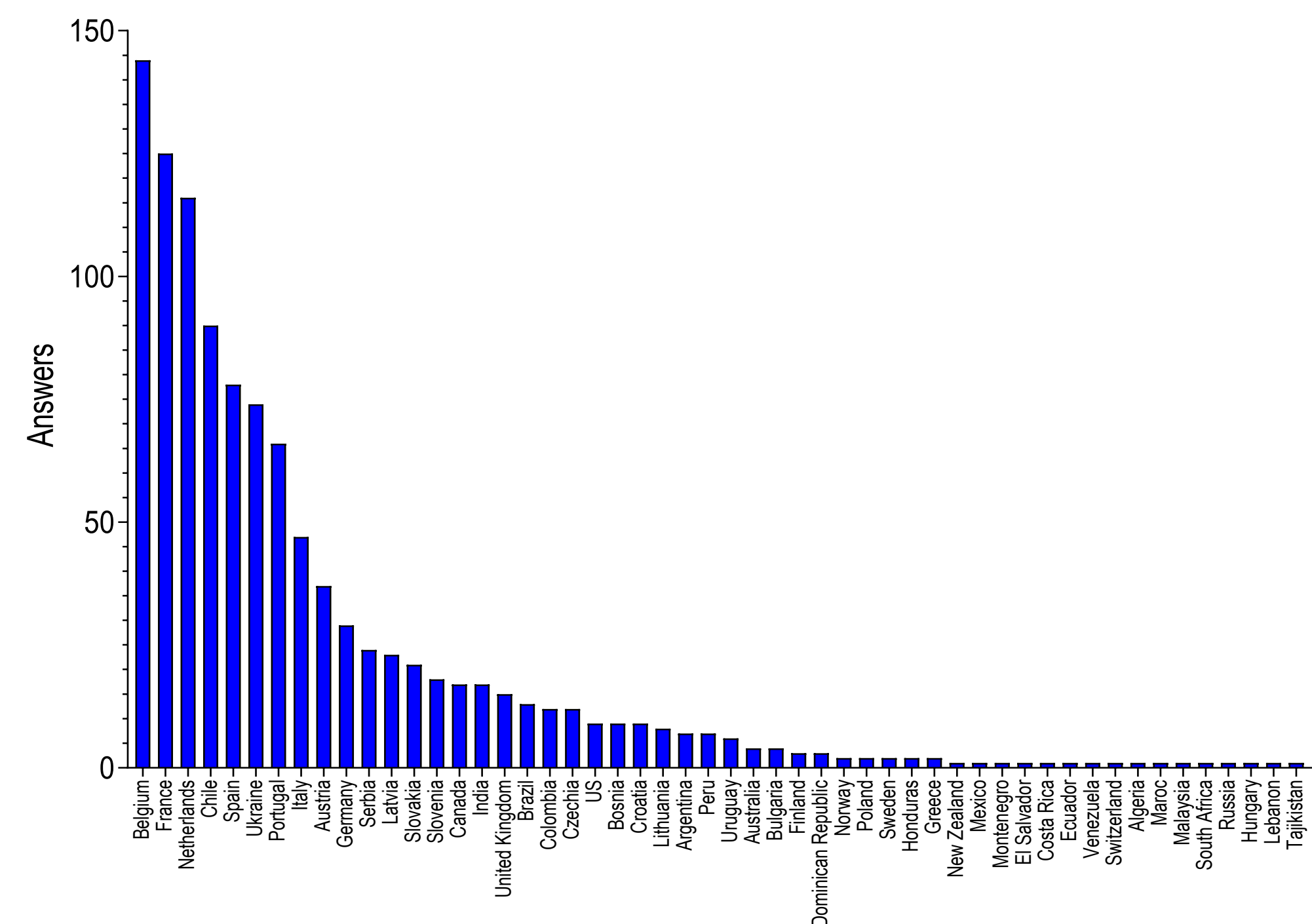
SARS-CoV-2 may be particularly dangerous for PH patients due to risk of pulmonary embolism and pulmonary vasculitis. Cancellation of non-urgent care for patients with chronic diseases was frequent during the pandemics.

We designed an international patient survey in the early phase of the COVID-19 pandemic to evaluate:

- How PH patients were affected by the COVID-19,
- How was the evolution of PH during lockdown
- What was the impact of COVID-19 on PH patients care\*

by using an online questionnaire open from 22/5/2020 to 28/6/2020 translated in 16 languages.

We received 1073 answers from 52 countries (mainly in Europe). 96% were adult patients and 4% paediatric patients). 92% of the patients reported a diagnostic of PAH or CTEPH. Most of the patients (87%) received oral therapy and 21% received parenteral therapy.

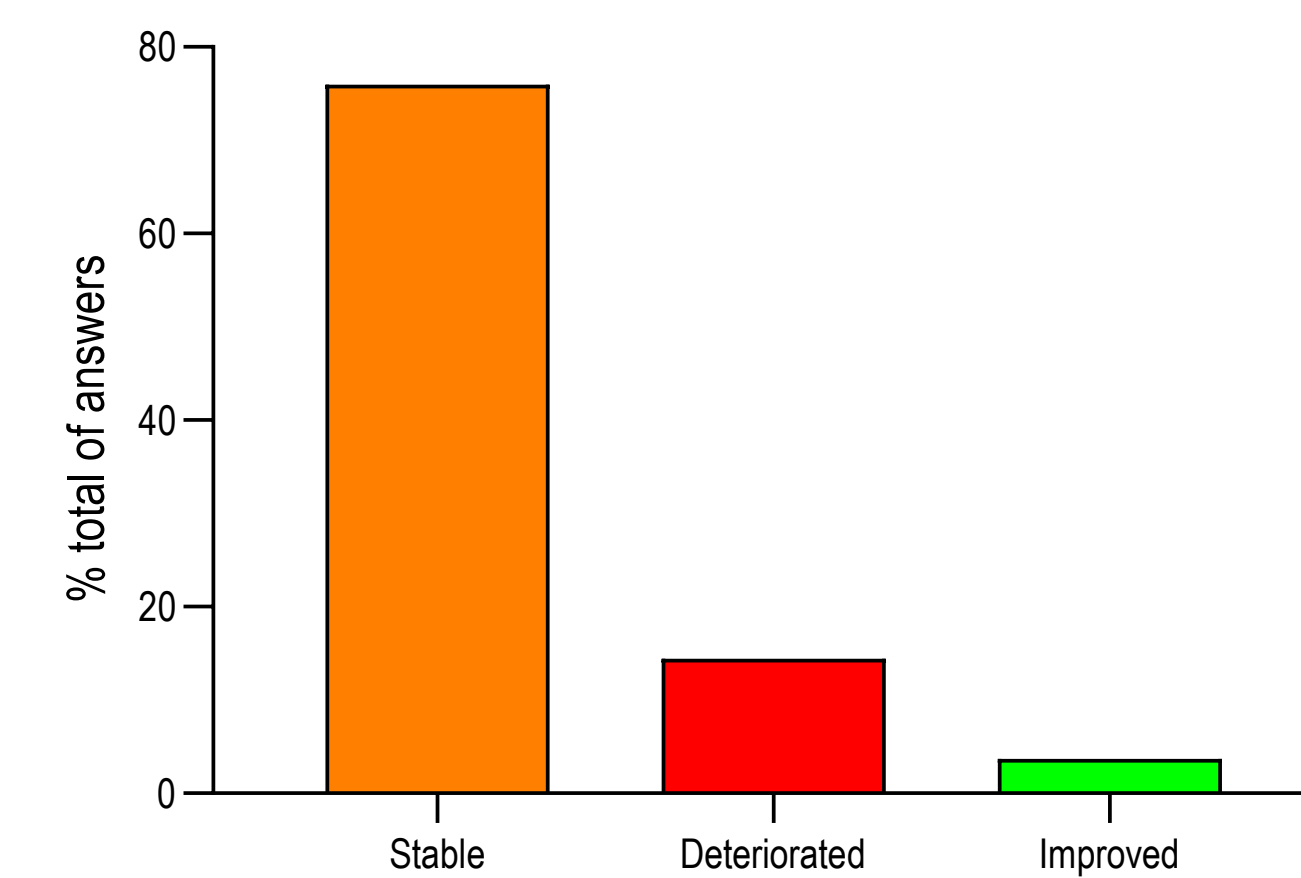


**Figure 1.** Geographical distribution of the participants.

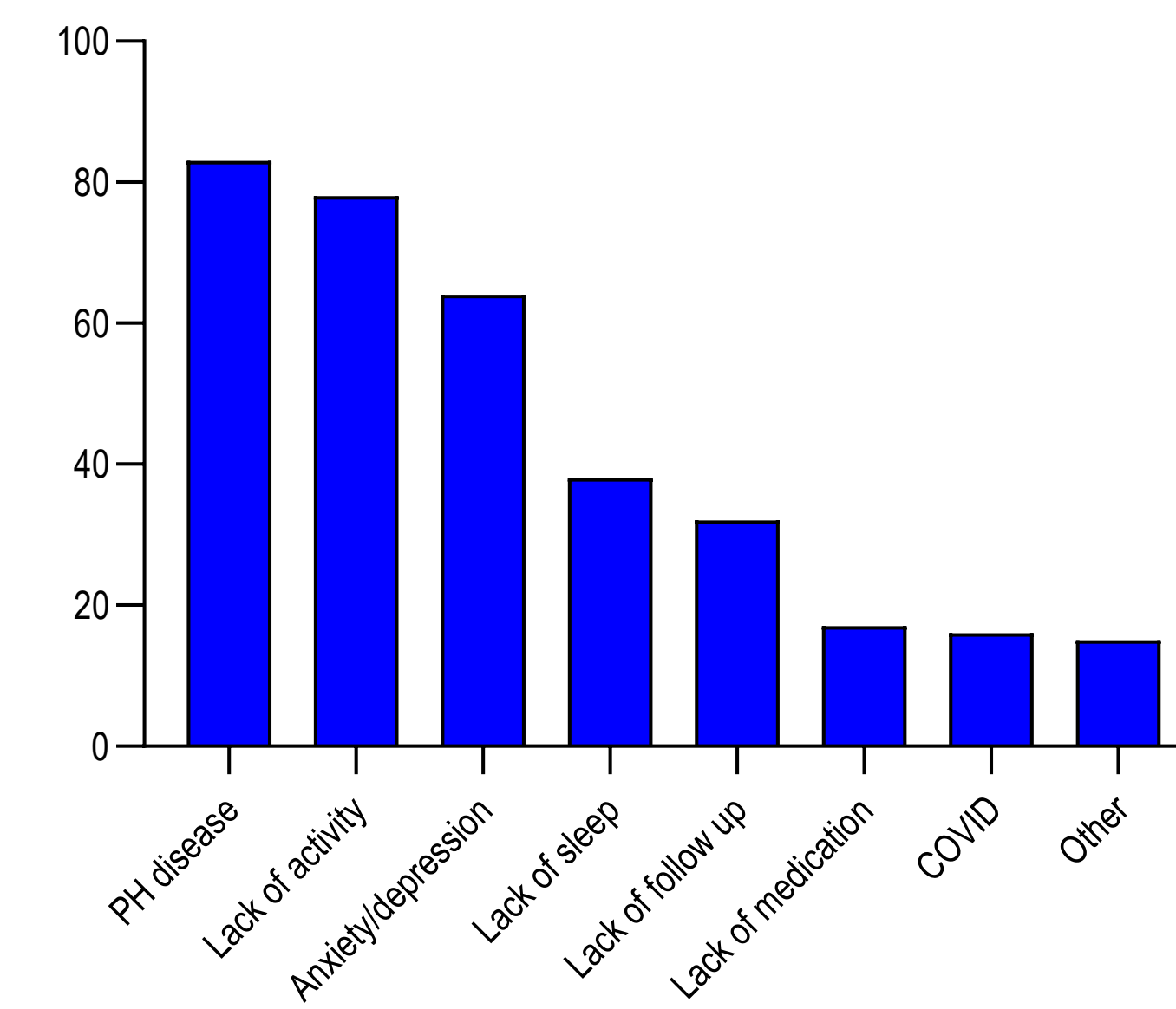
## Main results

Only 13 patients (1%) reported hospitalization for COVID-19, of which 2 patients reported hospitalization in intensive care units. No death was reported. 4% were hospitalized due to their PH condition (from whom 14% hospitalized in ICU).

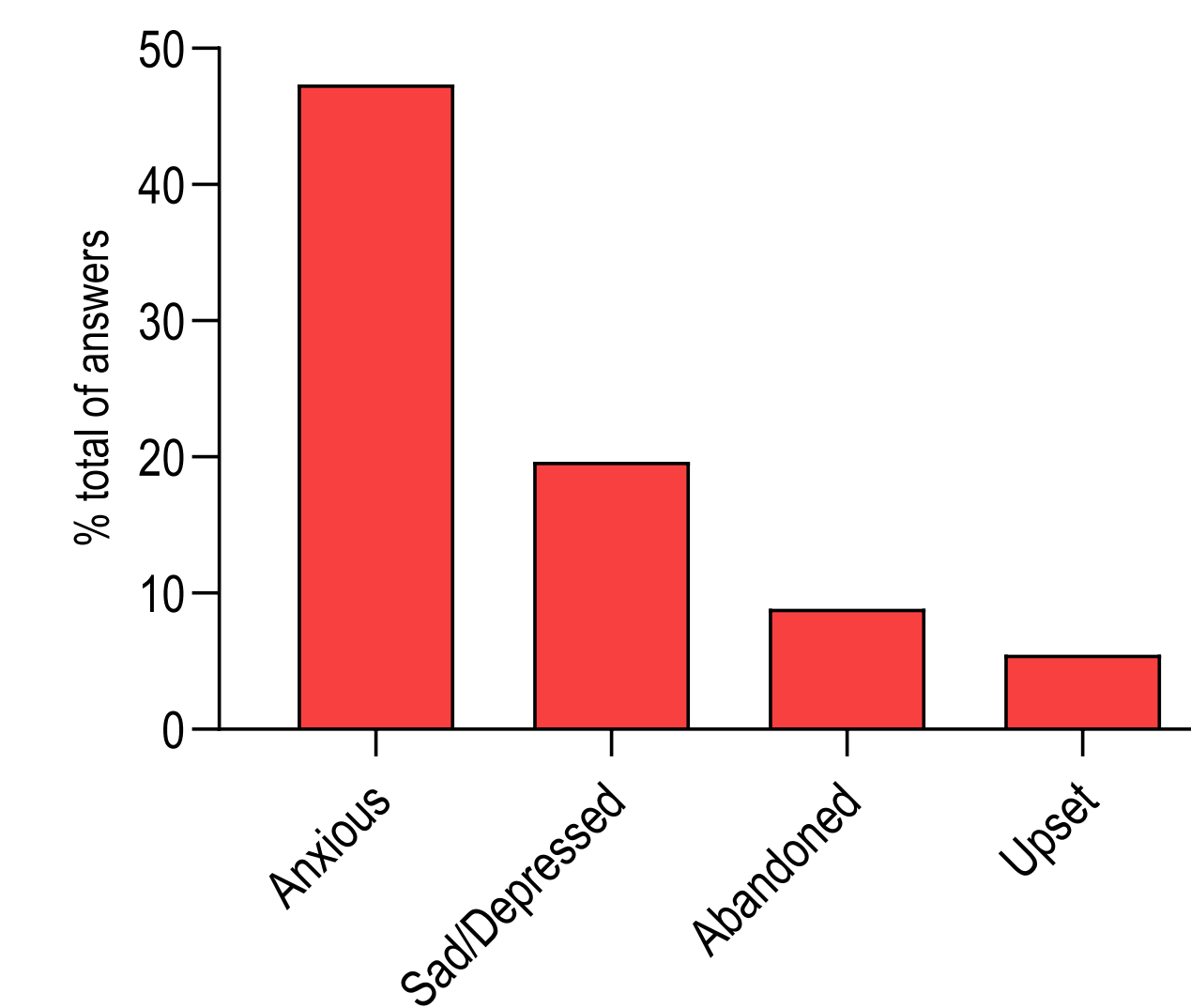
14% of the patients experienced deterioration of their health status.



**Figure 2.** Health status evolution of PH patients during the early phase of the pandemic.



**Figure 3.** Reported causes of health deterioration. Health problems related to PH were far more frequent than due to COVID.



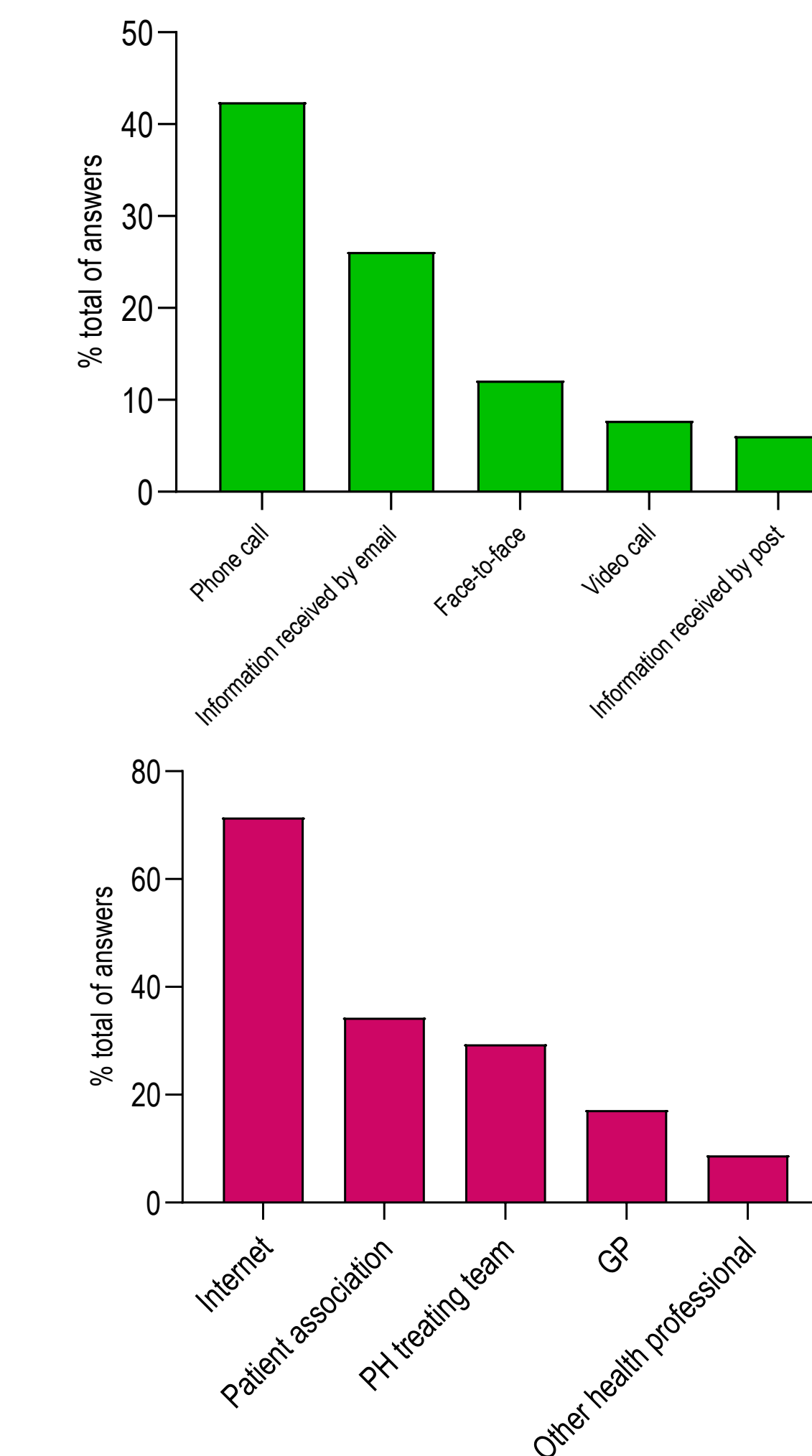
**Figure 4.** Feelings of the patients concerning evolution of their health status

## Main results

### Continuity of care assessment by patients

Difficulty to join the PH treating team	11%
Difficulty to join other health professionals	9%
Difficulty to receive PH specific medications	16%
Cancellation of medical appointments	49%
Cancellation of appointments without rescheduling or other instructions	13%
Treatment interruption due to shortage of medications	3%
Interruption of IV medication due to shortage	0.2%

Remote consultations were frequent during the early phase of the pandemic. Only 12% reported face-to-face contact with their PH team and 81% remotely. Main sources of information for patients was the internet and PH patient associations.



**Figure 5.** Consultation methods during the early phase of the pandemic.

**Figure 6.** Main sources of information concerning PH health status and COVID-19.

\*The results of the survey has been published: Godinas L, Iyer K, Meszaros G, et al. PH CARE COVID survey: an international patient survey on the care for pulmonary hypertension patients during the early phase of the COVID-19 pandemic. J Rare Dis. 2021 May 1;16(1):196. doi: 10.1186/s13023-021-01752-1.

## Conclusions

During the early phase of the pandemic, PH related problems were 4 time more common than COVID-19 related problems. PH patients experienced health deterioration, mood disorders, difficulties to join their PH team, interruption of care and shortage of vital medications. Remote consultations were used to maintain contact with patients. Patients associations could play an important role to spread reliable medical information. These data could be of interest for further planning of strategies and organization of PH centres to ensure continuity of care and adequate communications with patients