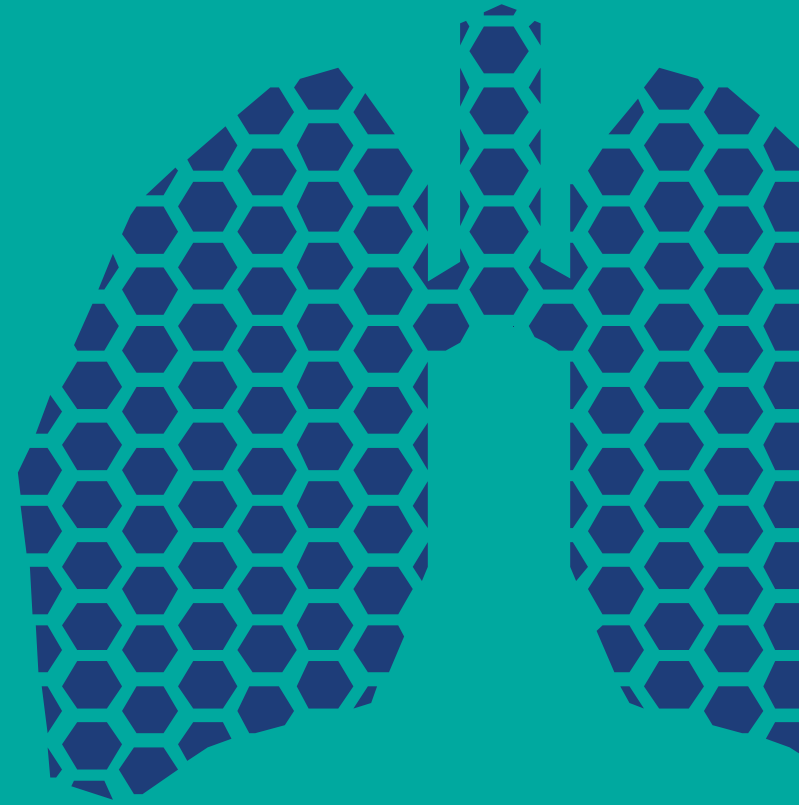


ACCESS TO OXYGEN THERAPY FOR PULMONARY FIBROSIS PATIENTS ACROSS EUROPE - SURVEY



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Alba Ubide

Overview

The European Lung Foundation (ELF) and European Pulmonary Fibrosis Federation (EU-IPFF) is carrying out a **survey of pulmonary fibrosis patients' access to oxygen therapy across Europe**. We aim to understand the situation in individual countries in order to advocate for change to benefit people living with the disease



WHAT?



HOW?

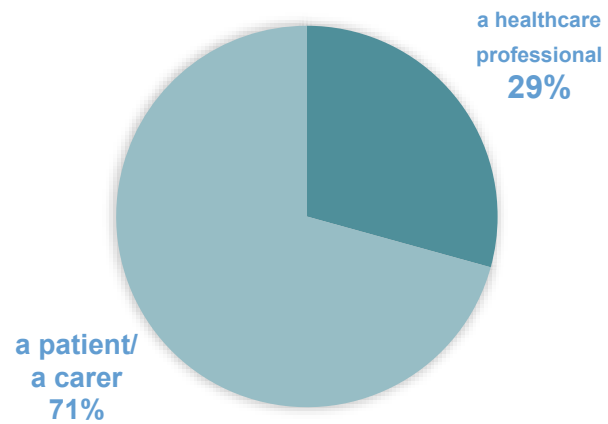


WHY?

General demographics data

Respondents

RESPONDENTS

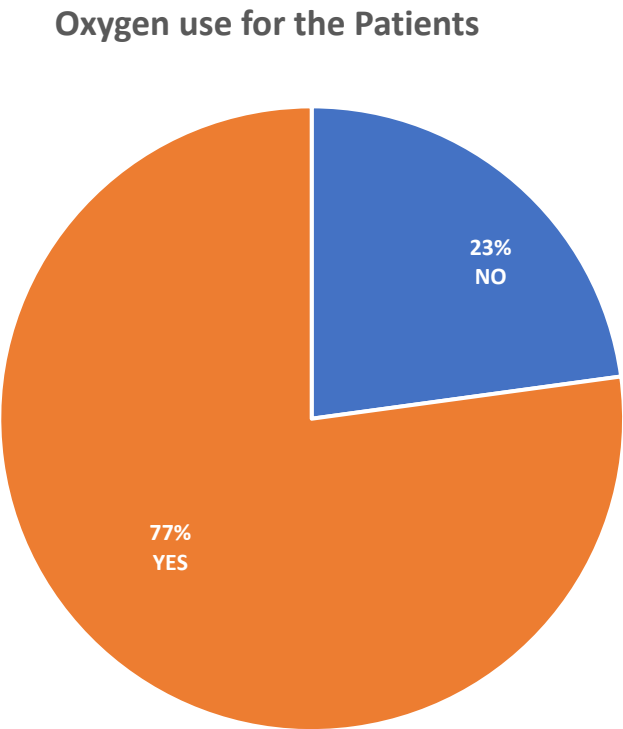
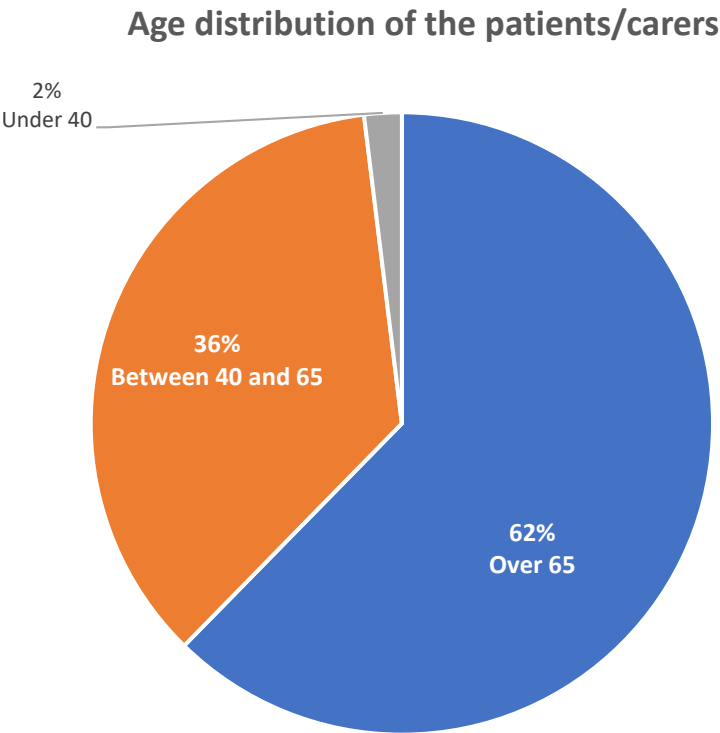
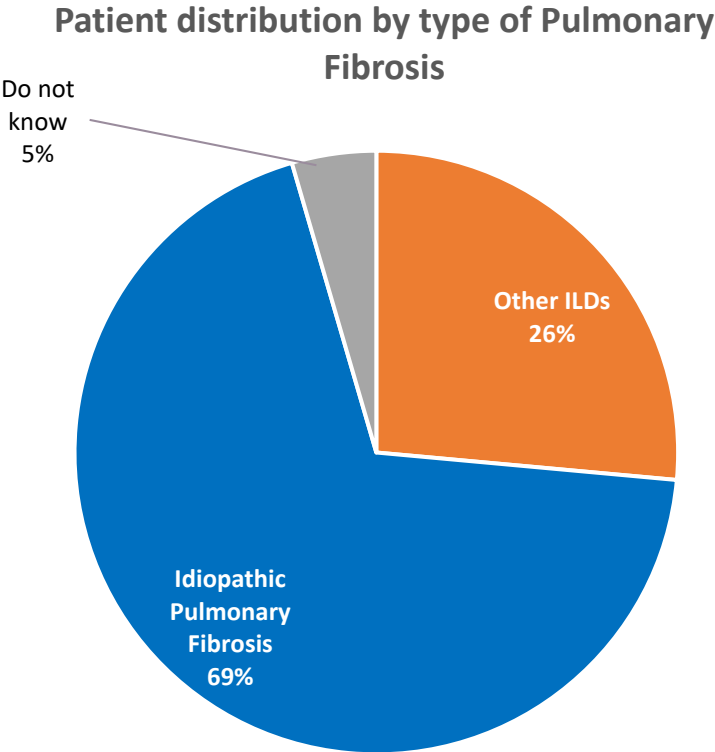


Austria
Belgium
Bulgaria
France*
Germany
Greece
Ireland
Italy
Norway
Poland
Romania
Spain
The Netherlands
United Kingdom



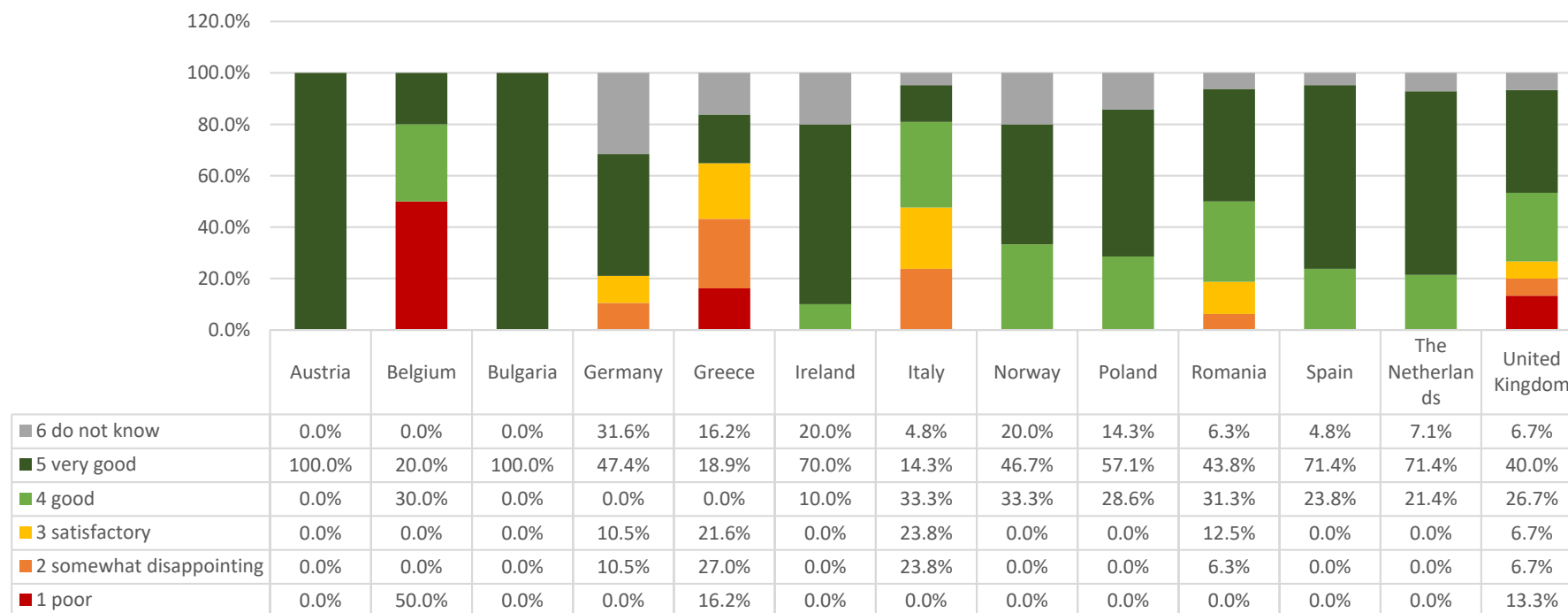
(*) did not reach minimum number of respondents for analysis

Respondents



Access to oxygen questions

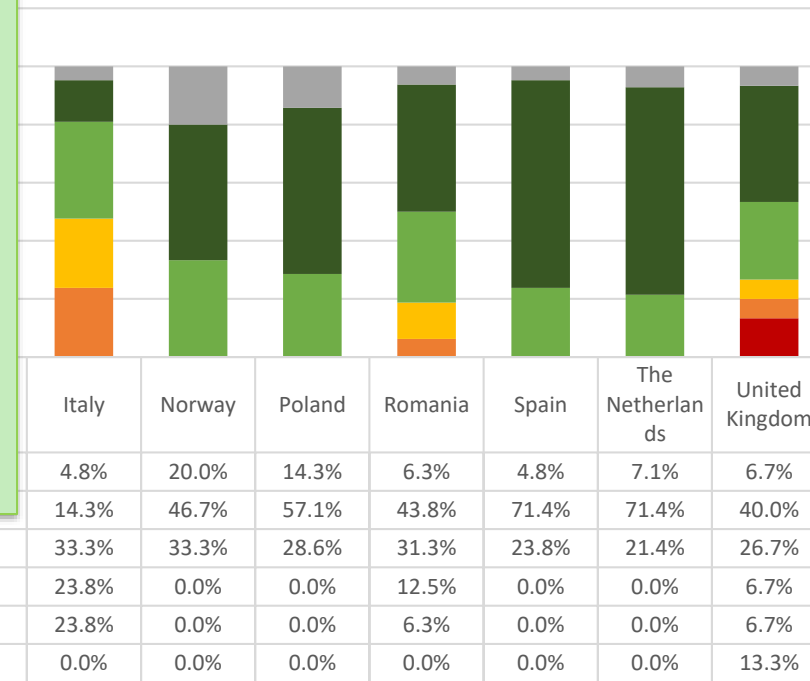
How would you rate pulmonary fibrosis patient's access to oxygen therapy **in hospital** in your country



Recommendations:

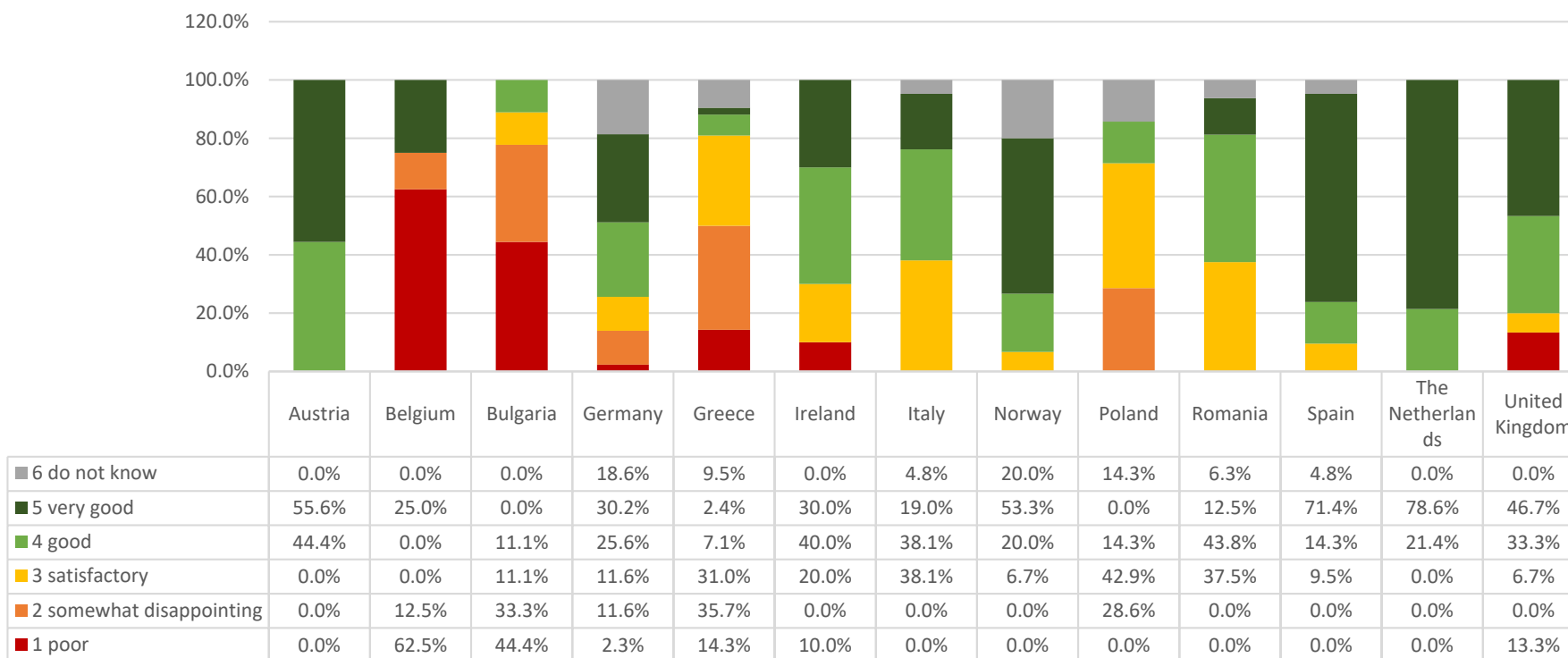
- Improve hospital equipment to guarantee O2 availability and access to “docking stations” for all patients.
- Improve information to medical staff to avoid confusion and poor understanding.
- Costs cover for all patients.
- Special attention to Greece.

Access to oxygen therapy in hospital in your



4 good	0.0%	30.0%	0.0%	0.0%	0.0%	10.0%
3 satisfactory	0.0%	0.0%	0.0%	10.5%	21.6%	0.0%
2 somewhat disappointing	0.0%	0.0%	0.0%	10.5%	27.0%	0.0%
1 poor	0.0%	50.0%	0.0%	0.0%	16.2%	0.0%

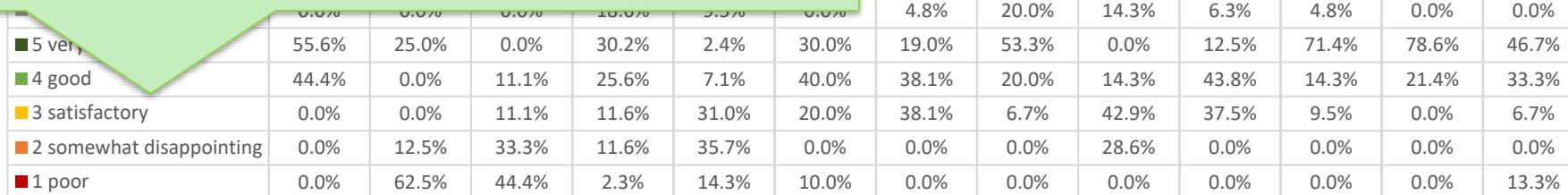
How would you rate pulmonary fibrosis patient's access to oxygen therapy **at home** in your country



Recommendations:

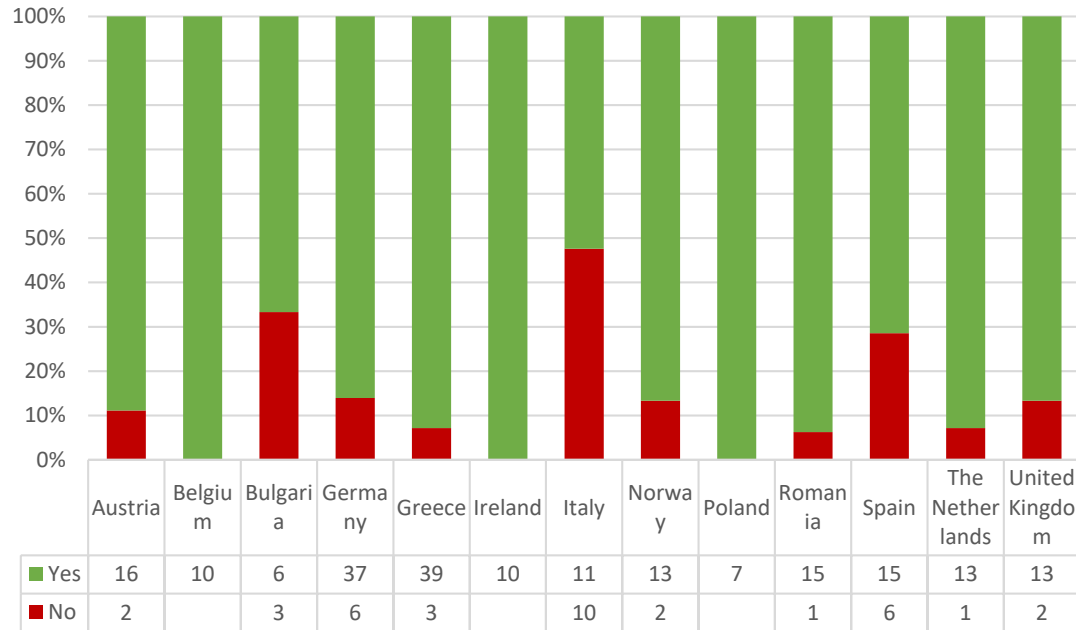
- Simplify procedures (bureaucracy!) and reduce waiting time.
- Costs cover (devices and power) for all patients.
- Improve instructions on use.
- Special attention to Belgium, Bulgaria, Greece and Poland.

Access to oxygen therapy at home in your

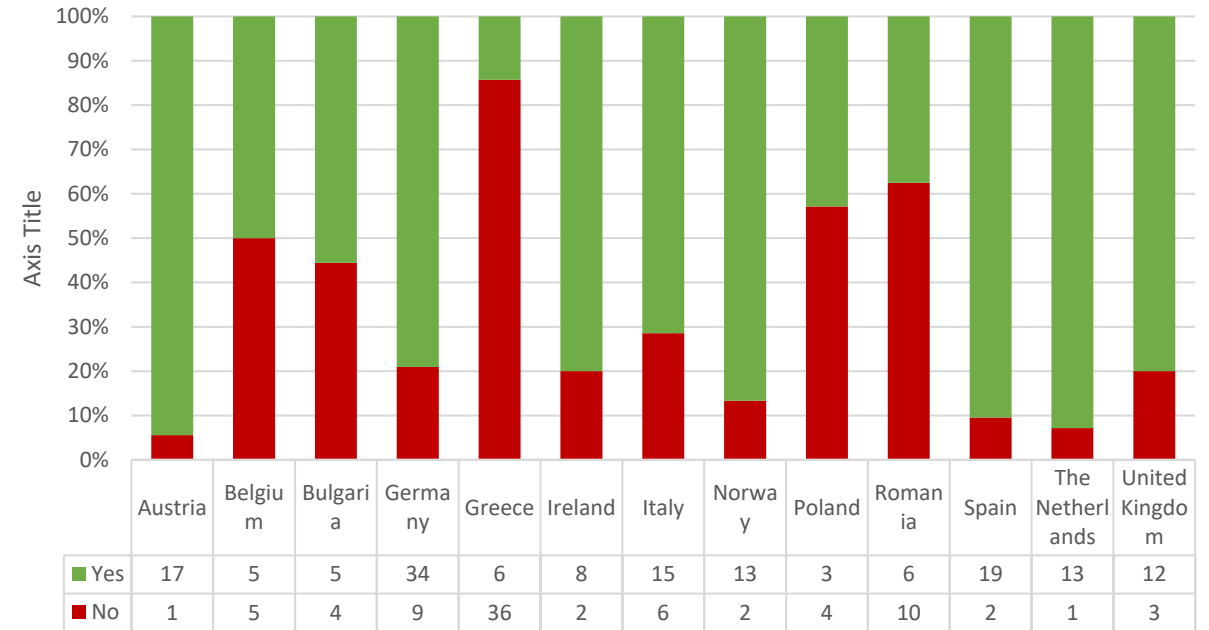


Access to oxygen supplies

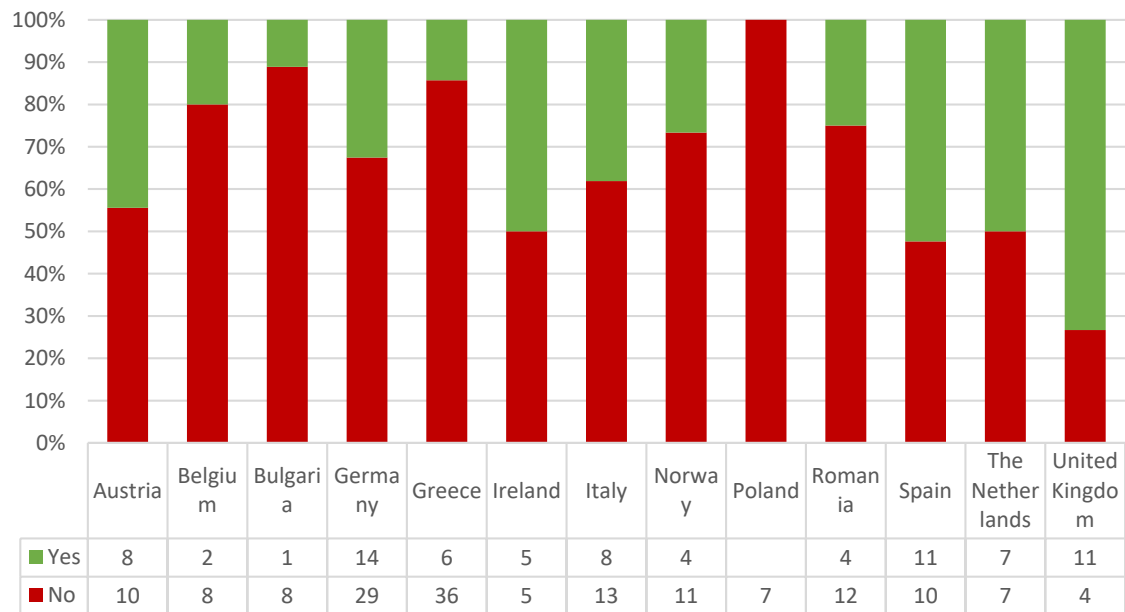
Access to Oxygen concentrator system: stationary at home



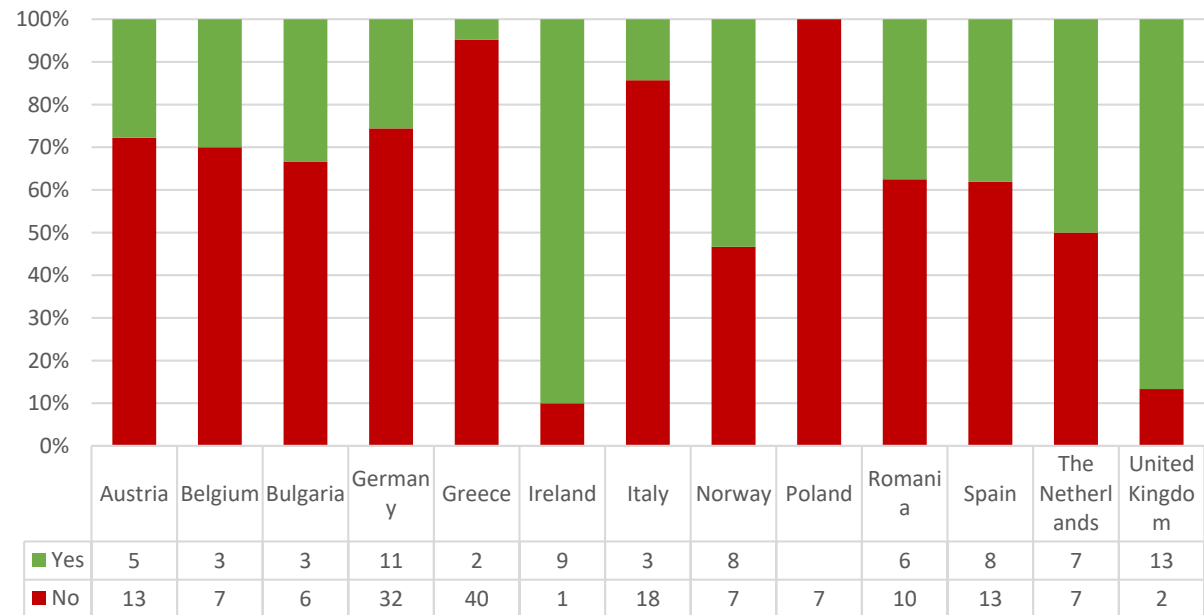
Access to Oxygen concentrator system: portable (outside home)



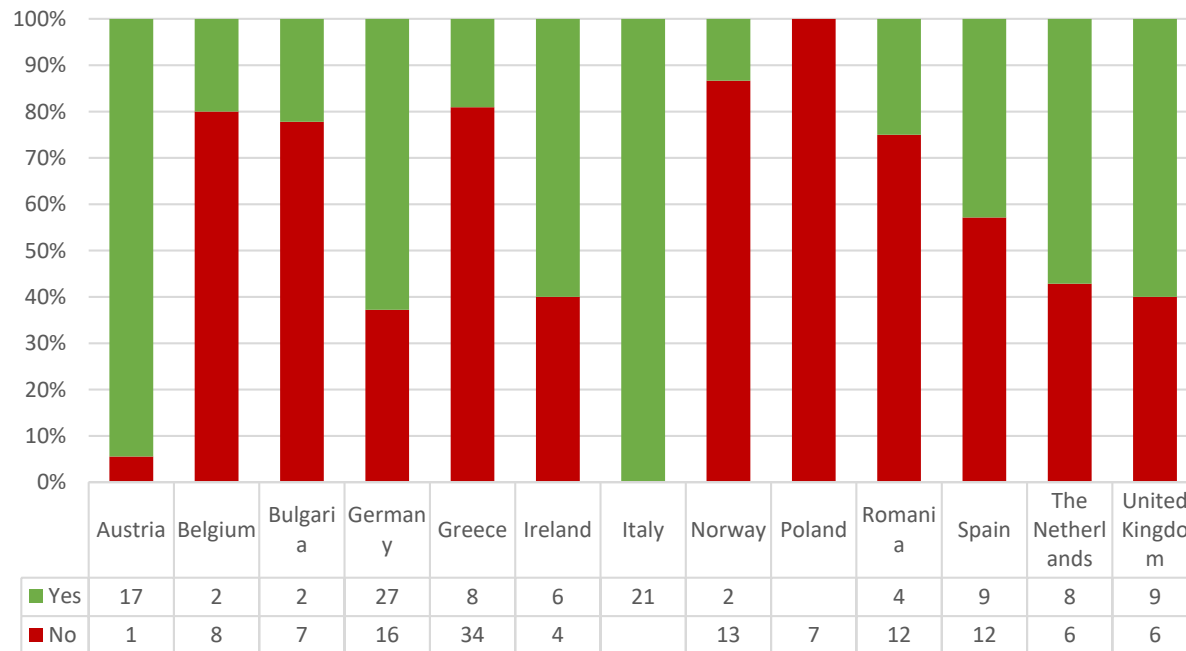
Access to compressed oxygen gas cylinder: stationary



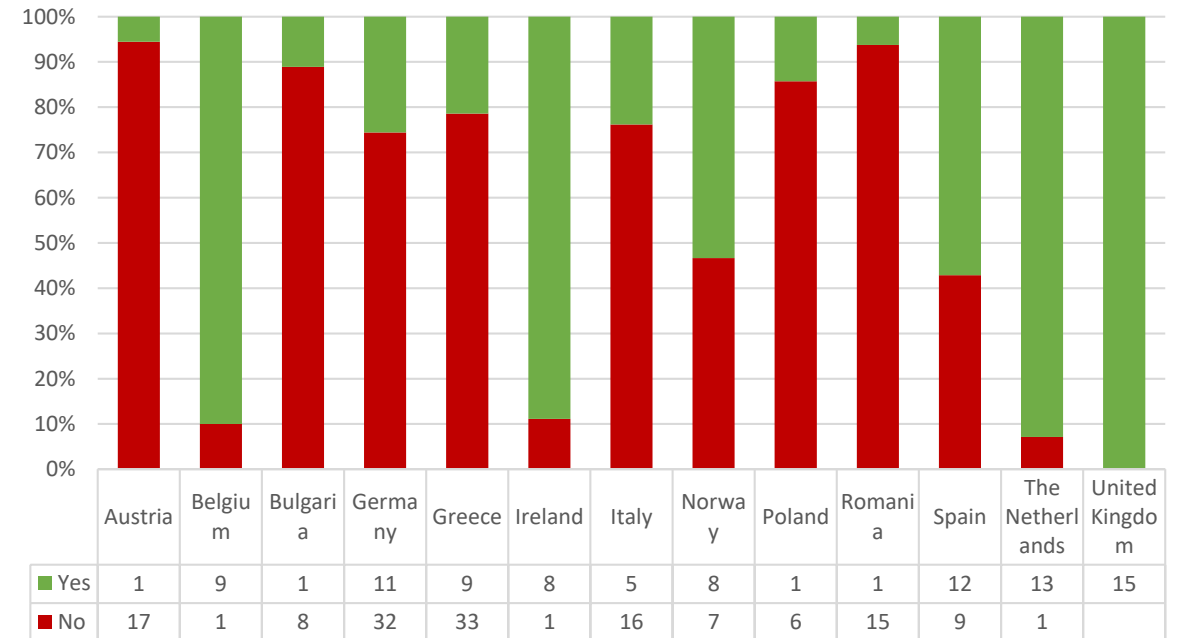
Access to compressed oxygen gas cylinder: portable



Access to liquid oxygen system: stationary and portable cylinders



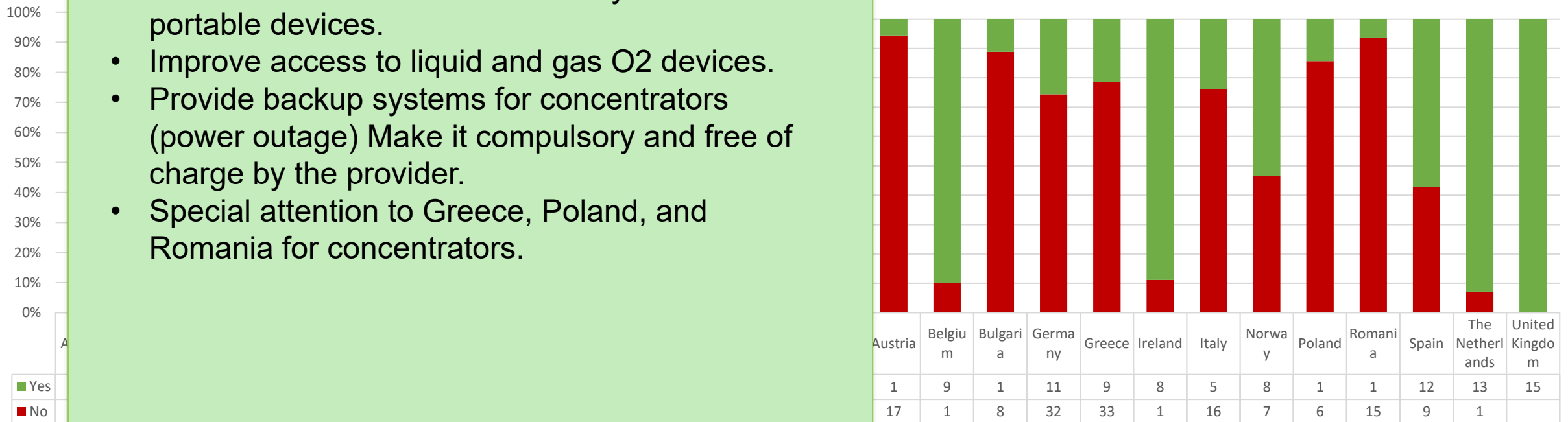
Do patients have back up system in case of power outage if using oxygen concentrator?



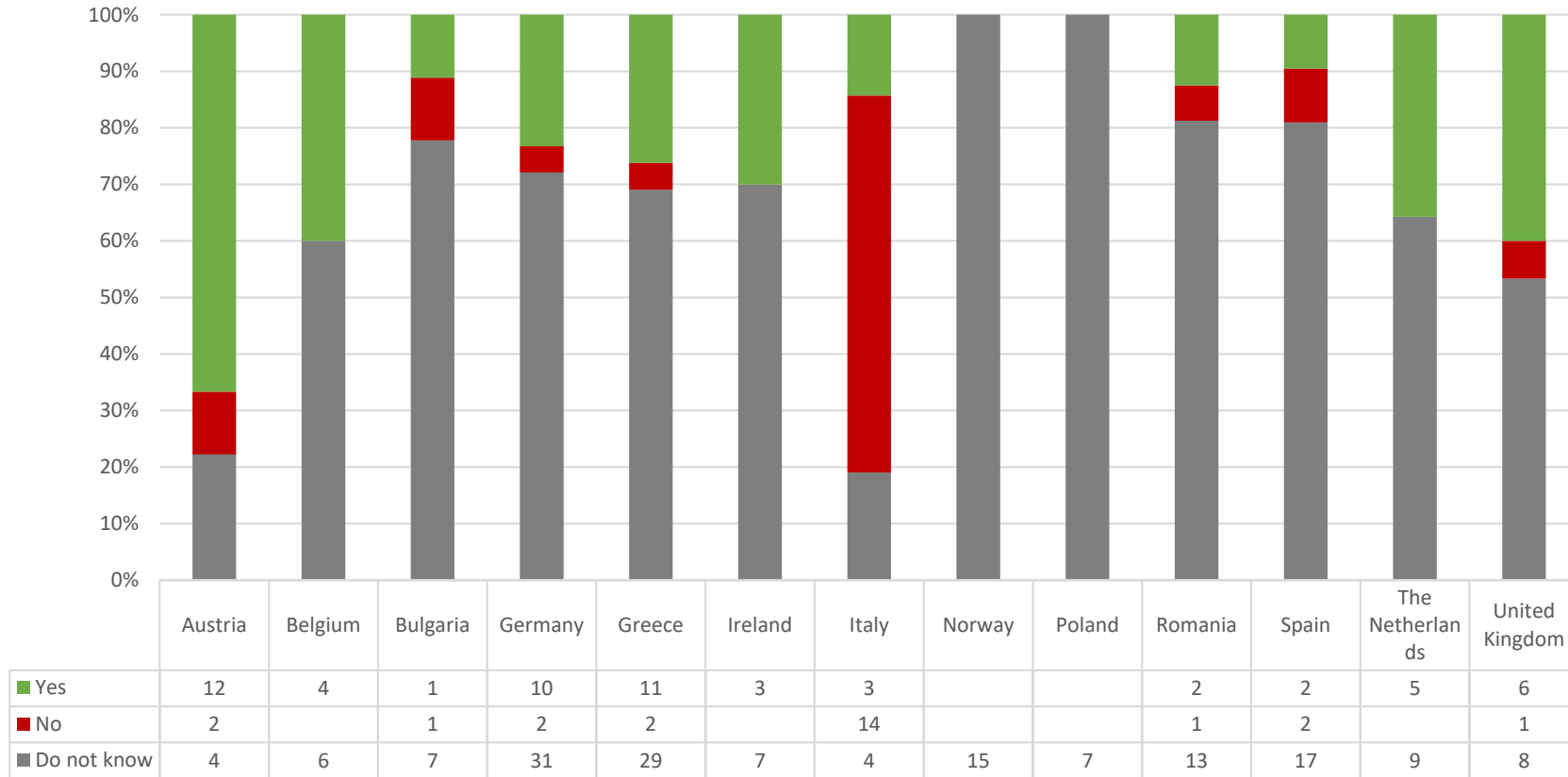
Recommendations:

- Facilitate access to both stationary and portable devices.
- Improve access to liquid and gas O2 devices.
- Provide backup systems for concentrators (power outage) Make it compulsory and free of charge by the provider.
- Special attention to Greece, Poland, and Romania for concentrators.

Do patients have back up system in case of power outage if using oxygen concentrator?



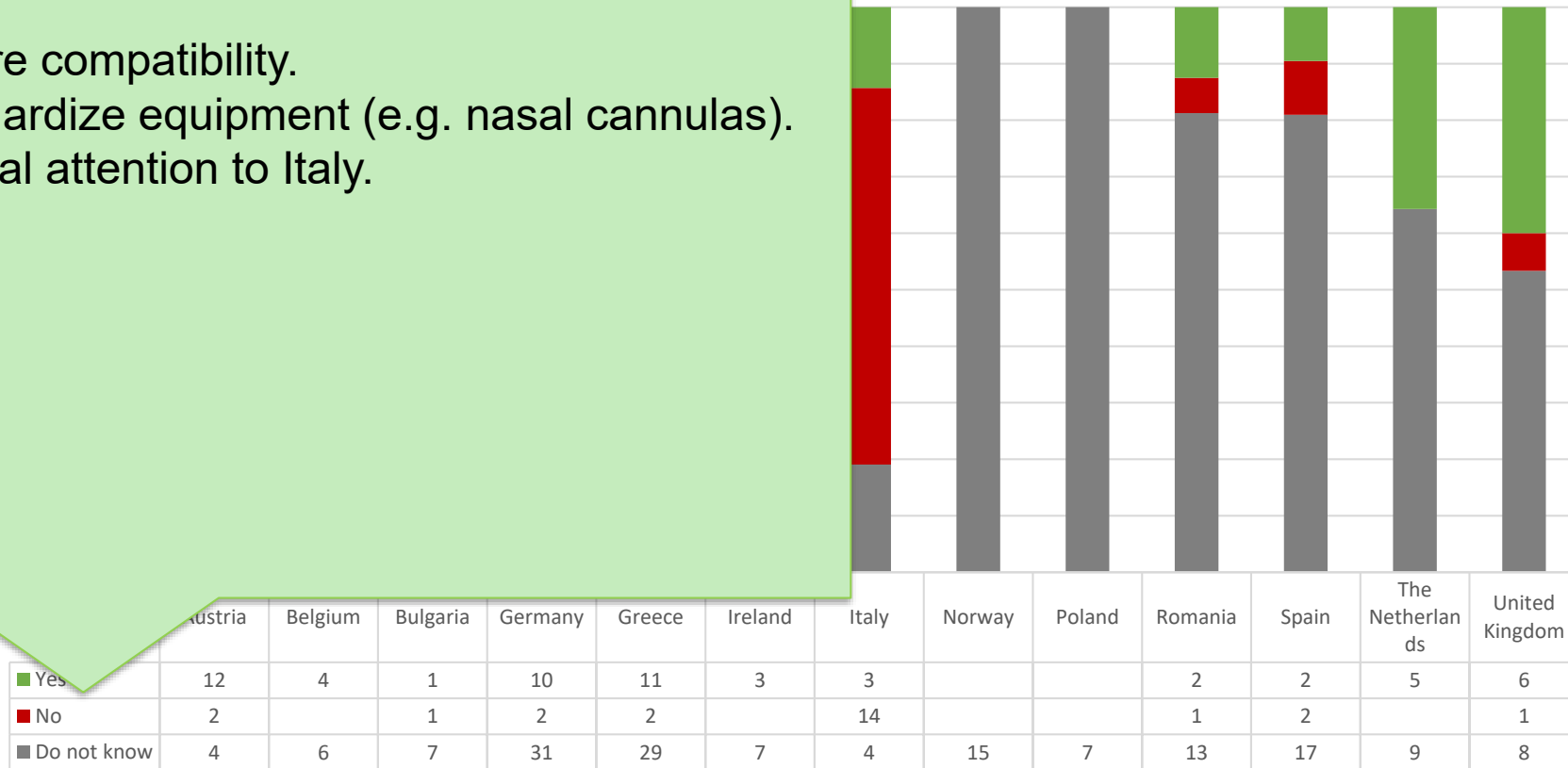
Do companies use similar/compatible types of oxygen equipment?



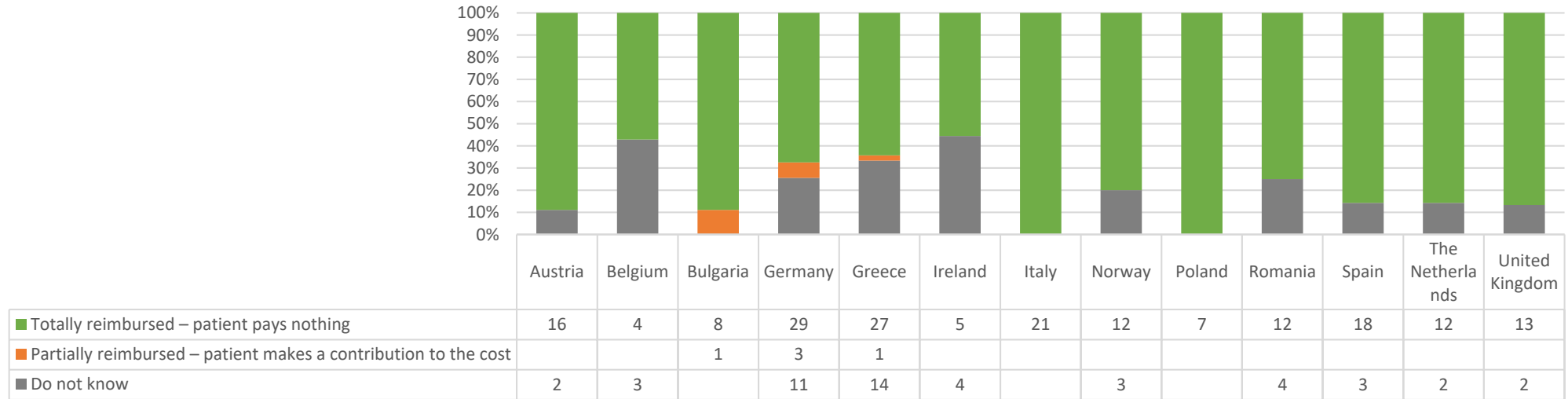
Recommendations:

- Ensure compatibility.
- Standardize equipment (e.g. nasal cannulas).
- Special attention to Italy.

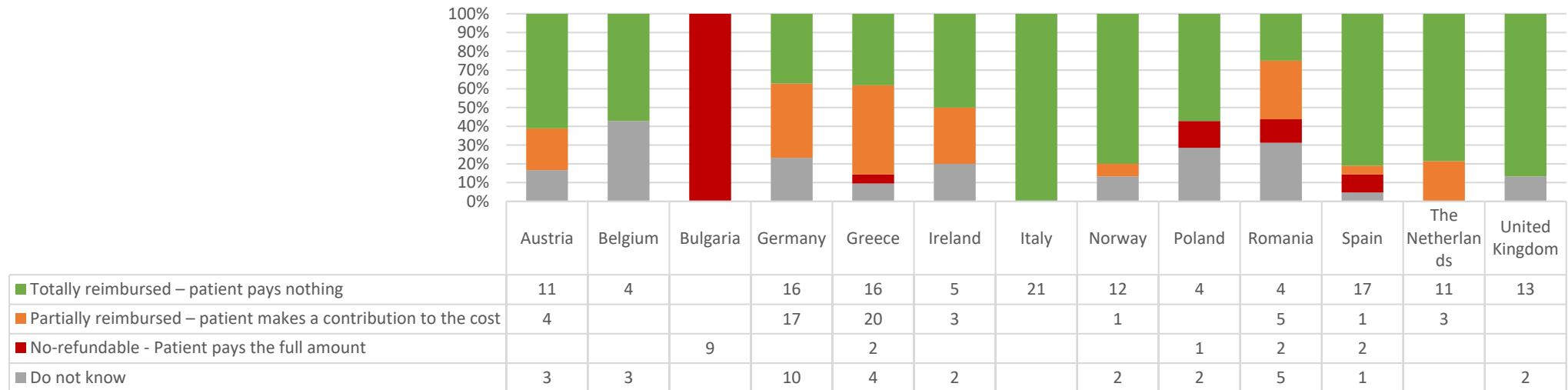
types of oxygen equipment?



Are oxygen costs reimbursed when in hospital?



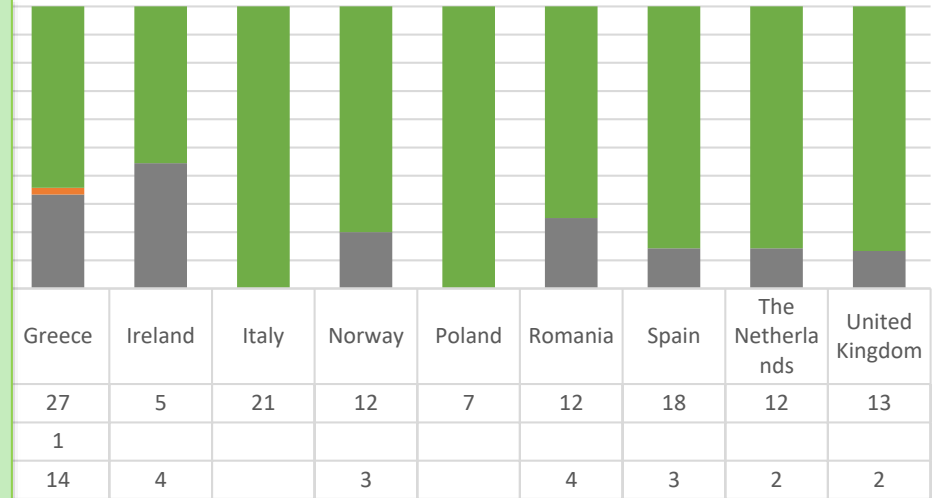
Are oxygen costs reimbursed when at home?



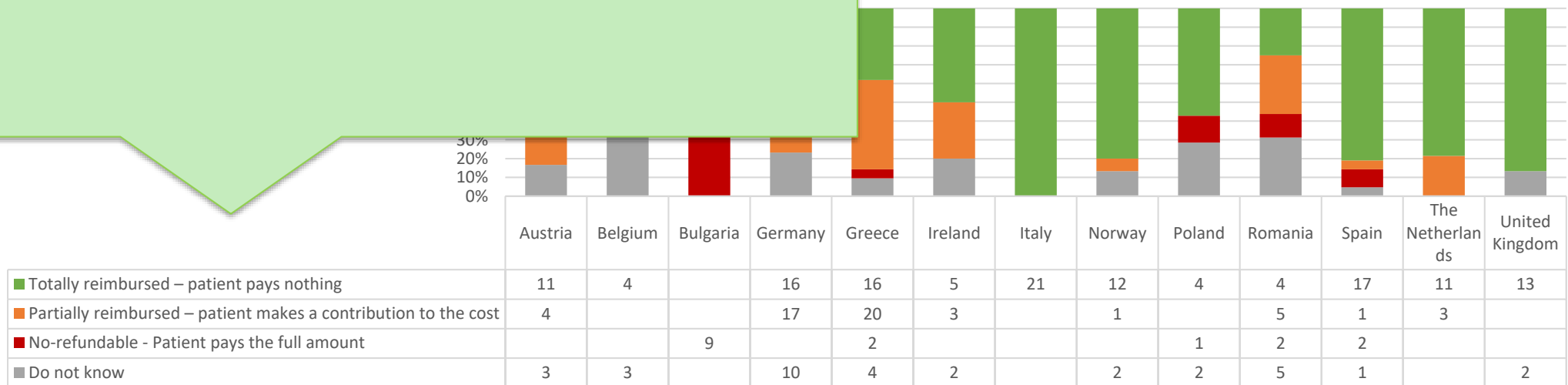
Are oxygen costs reimbursed when in hospital?

Recommendations:

- Should be completely free of charge in all countries, whether in hospital or at home.
- Special attention to Greece, Poland, Romania, and Spain and most particularly to Bulgaria.

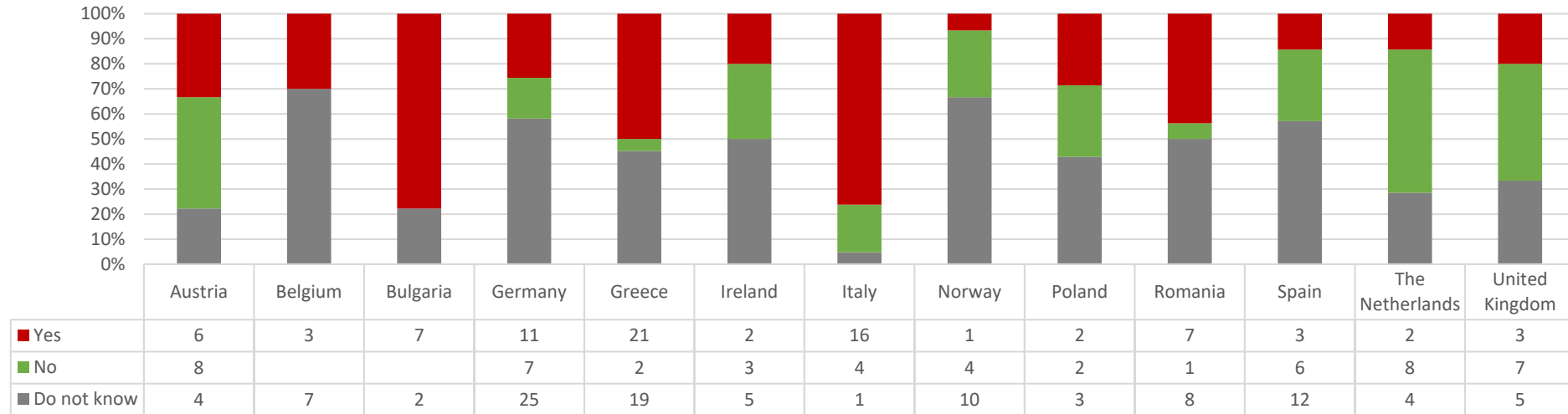


when at home?

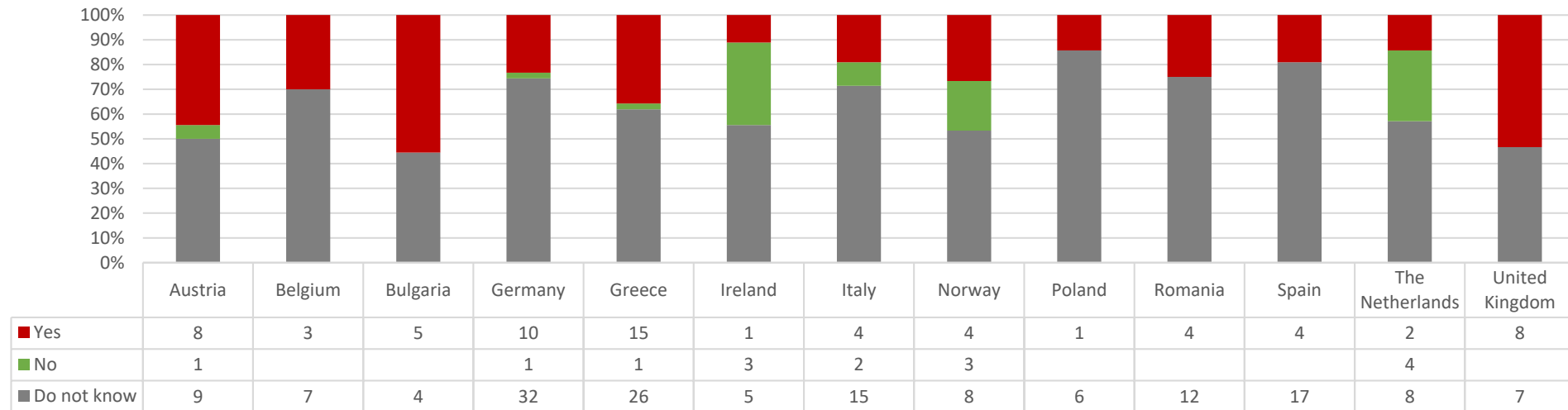


Issues with travelling

Do patients have problems obtaining oxygen while traveling in- country?

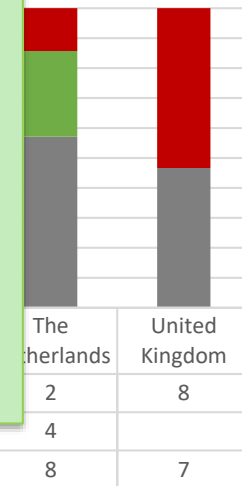
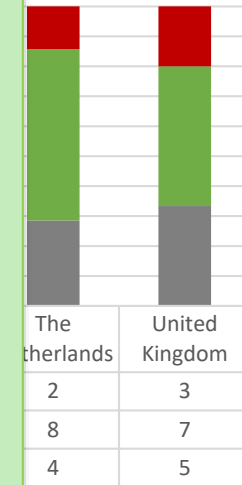
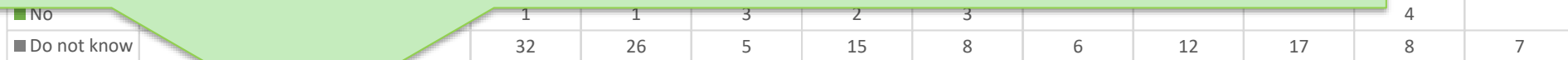


Do patients have problems obtaining oxygen while traveling abroad?

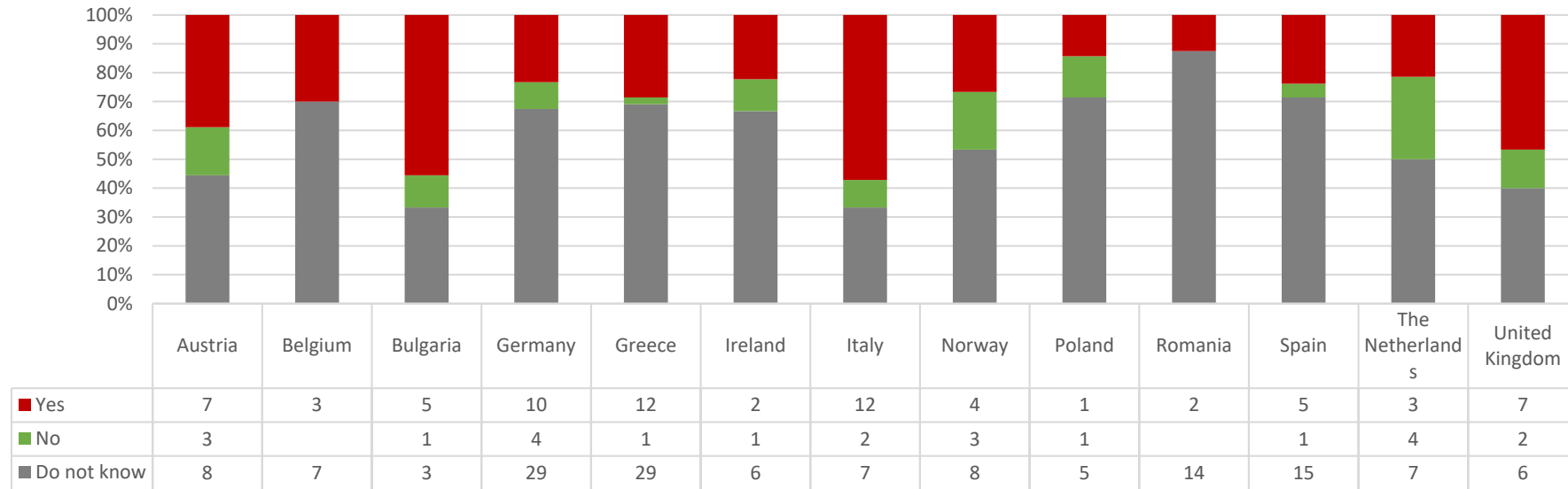


Recommendations:

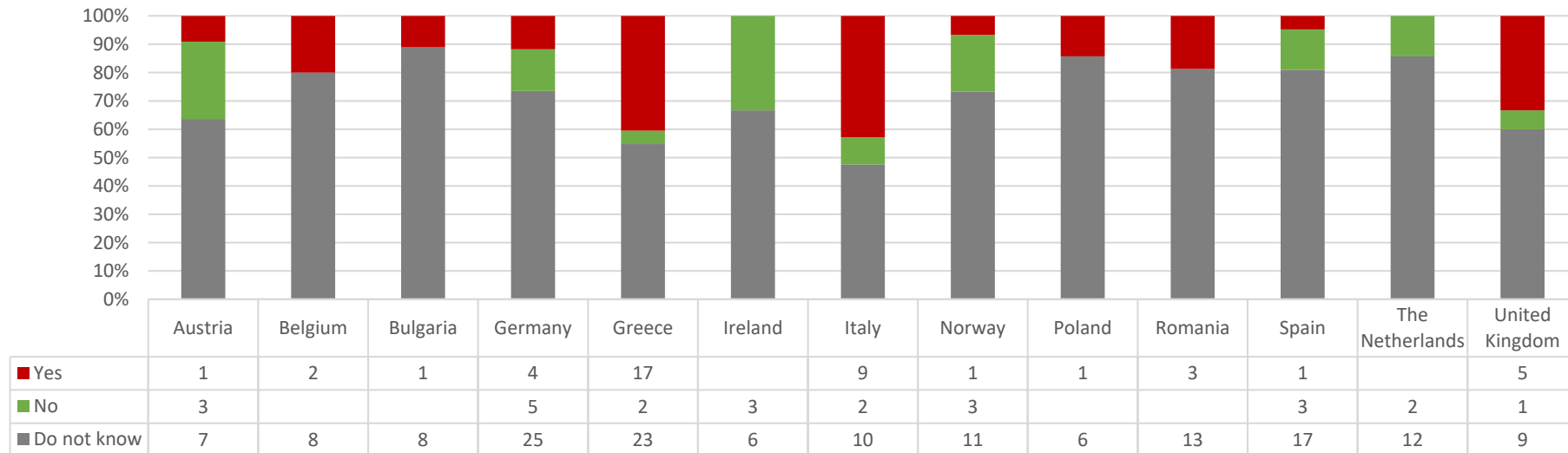
- Travelling is difficult for most, even inside the country; the difficulty increases when traveling abroad. Many respondents simply do not travel at all.
- In many countries patients have to pay for equipment (Bulgaria, Germany ..)
- Recommendations.
- Costs should be covered by health insurance.
- Improve autonomy and provide refill stations (e.g. in health facilities, pharmacies, post offices/administrations, ...).
- Improve the design, weight, and shape of portable devices.
- Standardize procedures for all means of transport (specifically airlines)
- Special attention to Greece (“there is no planning and no interest to allow a patient/ a carer to move.”), Romania (ambulances with oxygen must be requested, which do not always transport the patient to the specialist hospital) and Italy, to a lesser degree to Spain, Belgium, Poland, Germany, and Bulgaria.



Do patients have problems obtaining oxygen while traveling by air?



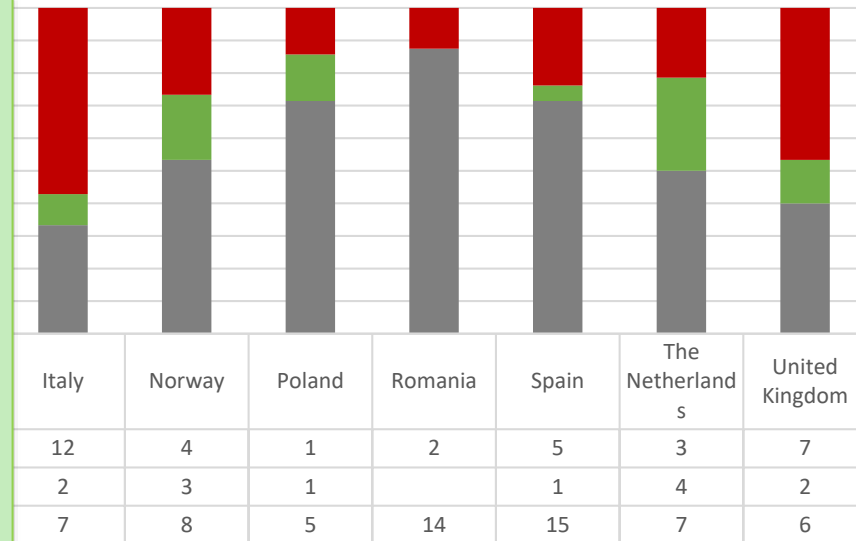
Do patients have problems obtaining oxygen while traveling by sea?



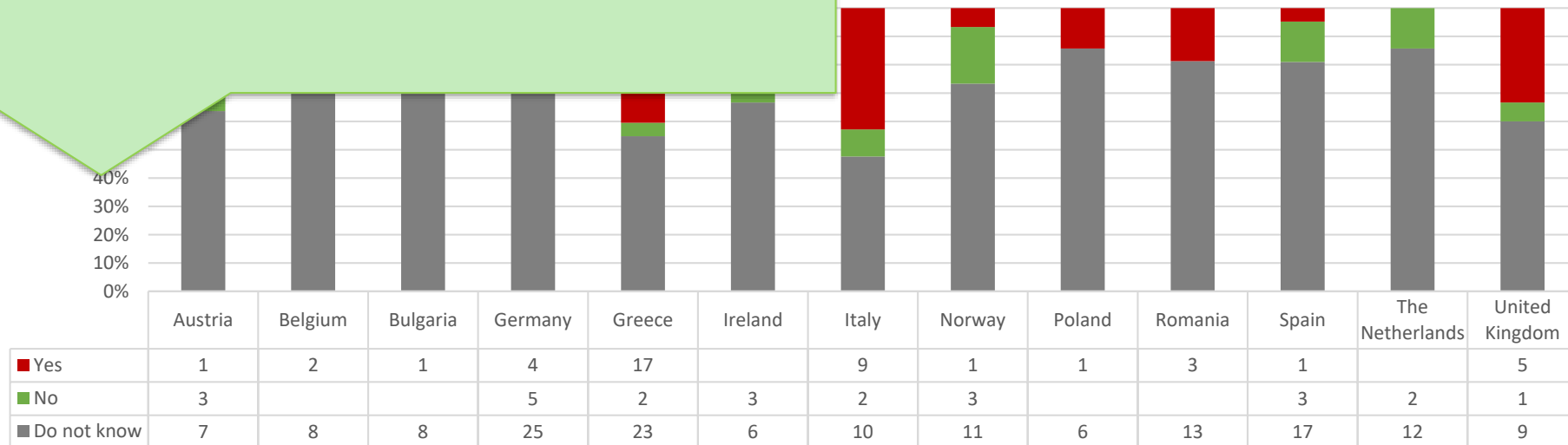
Do patients have problems obtaining oxygen while traveling by air?

Recommendations:

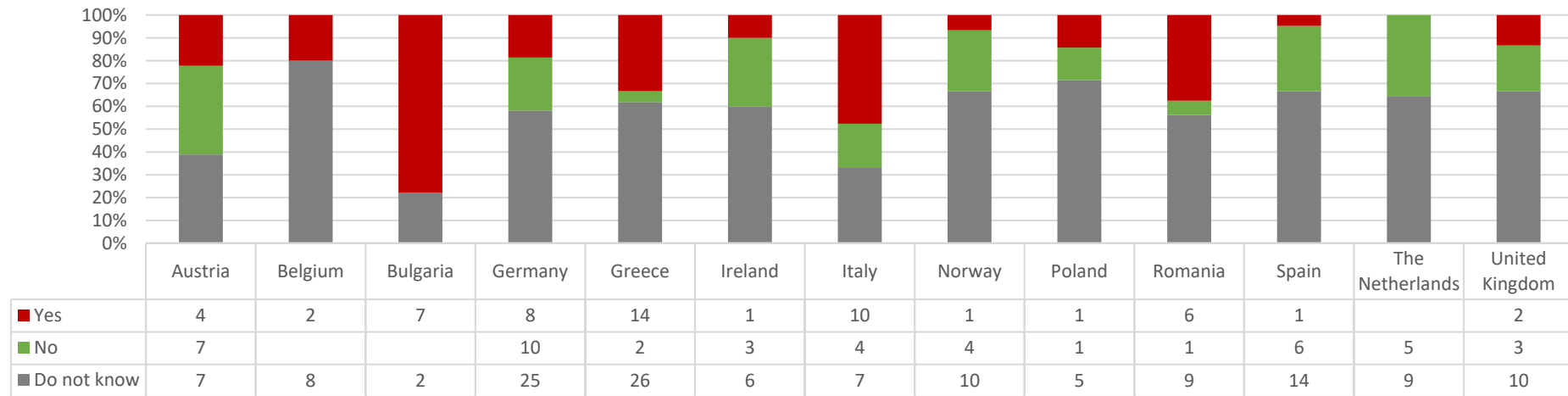
- Allow and facilitate access to air and sea travel.
- Standardize procedures, reduce bureaucracy.
- Prohibit extra costs.
- Provide refilling, especially on long hauls.



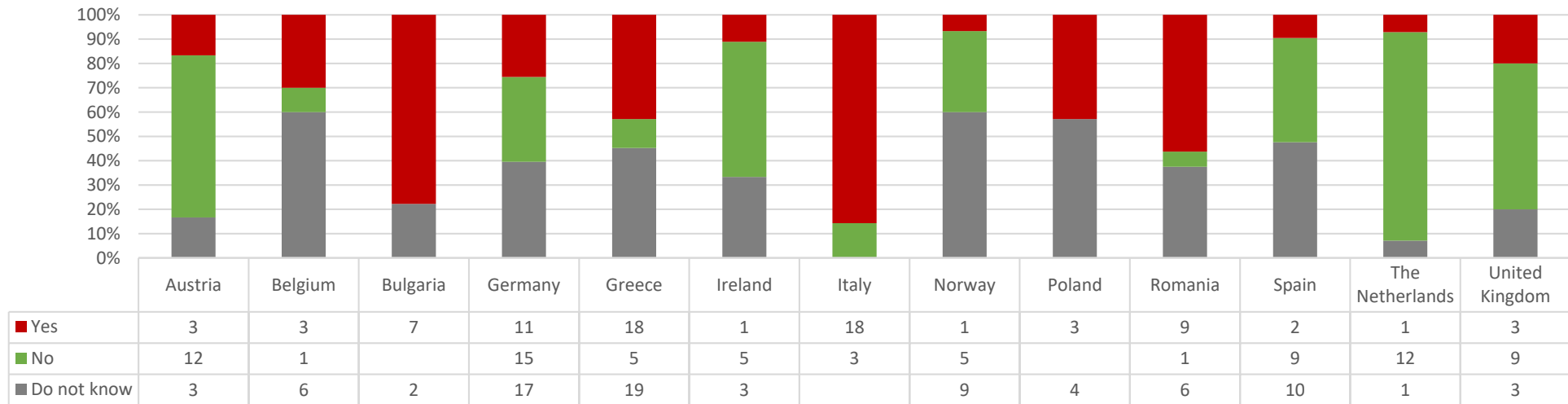
Do patients have problems obtaining oxygen while traveling by sea?



Do patients have problems obtaining oxygen while traveling by rail?



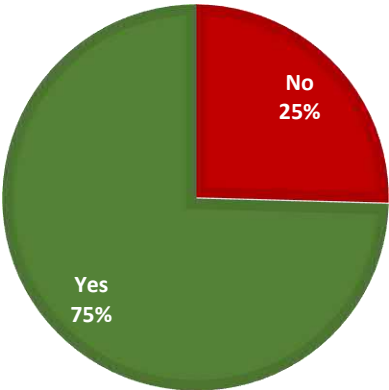
Do patients have problems obtaining oxygen while traveling by road?



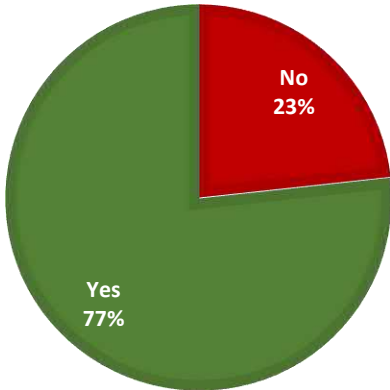
Confidence

Patients' perspective on oxygen use

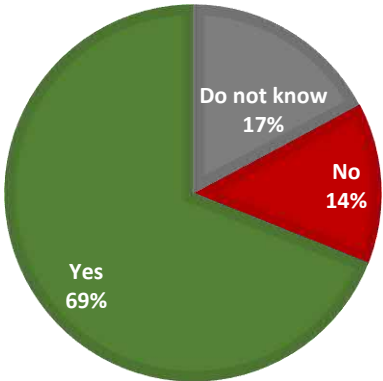
WERE YOU INSTRUCTED ON HOW TO USE
OXYGEN EQUIPMENT SAFELY AND EFFICIENTLY?



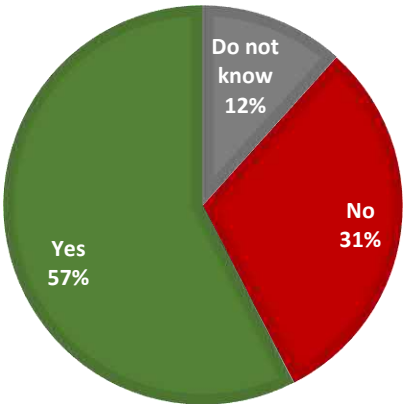
DO YOU KNOW WHEN YOU SHOULD USE THE
SUPPLEMENTARY OXYGEN AND HOW MUCH TO USE ?



DO YOU USE SUPPLEMENTARY OXYGEN
EVERY TIME YOU KNOW YOU SHOULD?



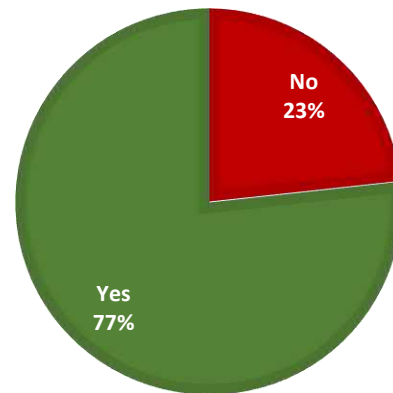
DO YOU FEEL COMFORTABLE USING
SUPPLEMENTARY OXYGEN IN PUBLIC?



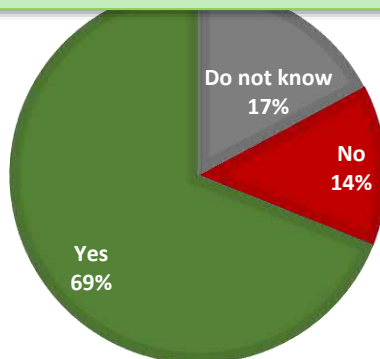
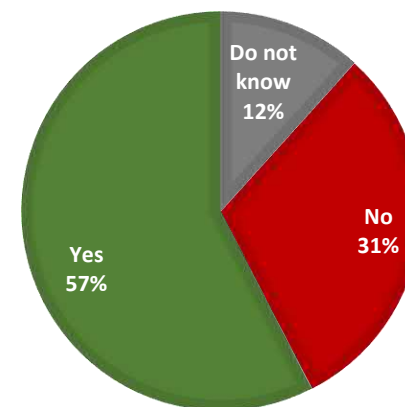
Recommendations:

- Need for better guidelines and follow-up from both healthcare professionals and providers, to avoid the “do it yourself” approach and feeling of helplessness.
- Need for medical/psychological support.
- Improve the quality and comfort of use of the equipment, noise is considered a public nuisance.

KNOW WHEN YOU SHOULD USE THE
ARY OXYGEN AND HOW MUCH TO USE ?



DO YOU FEEL COMFORTABLE USING
SUPPLEMENTARY OXYGEN IN PUBLIC?



Conclusion

Conclusions

What's next?

Austria
Belgium
Bulgaria
France*
Germany
Greece
Ireland
Italy
Norway
Poland
Romania
Spain
The Netherlands
United Kingdom



ACCESS TO OXYGEN ... A BASIC HUMAN RIGHT!