

Atlas of Variance: Evaluation of Care Delivery to Patients with Chronic Intestinal Failure in Europe; A Focus on Home Parenteral Nutrition

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Background

- Chronic intestinal failure (IF) is a rare but life-altering condition occurring from extensive surgical resection, disease-associated loss of absorption or congenital diseases of the small intestine¹
- Loss in intestinal absorptive capacity can lead to malnutrition, dehydration and micronutrient depletion, which may require long-term parenteral support¹
- Chronic IF management is complex and aims to alleviate the daily burden of the condition through maximising the remnant intestinal absorptive capacity, and minimising the symptoms of malabsorption and the need for parenteral support^{1,2}
- Anecdotal reports show that the management of chronic IF can vary across countries in Europe. This non-interventional study aimed to characterise the standard of care (SoC) for adult patients with chronic IF in Europe
- We report the results on the provision and challenges of home parenteral nutrition (HPN)

Objectives

Primary objective:

- To describe the management of adult patients with chronic IF across Europe

Secondary objectives included:

- Describing the variation in SoC between European countries
- Identifying the goals of treatment for chronic IF from healthcare professionals' (HCP) perspectives

Methods

- HCPs involved in the management of adult patients with chronic IF (at least 10 patients over the past 5 years) were invited to complete an online quantitative survey during the period November 2020 to January 2021
- Data were collected from 12 European countries: Belgium, Croatia, Denmark, France, Italy, Norway, Poland, Portugal, Romania, Spain, Switzerland, UK
- Survey data were anonymised and pooled for analysis at European and country level. Responses were summarised as frequencies, ranks and percentages

Results

119 HCPs completed the survey across an estimated 58 centres (Table 1)

- Gastroenterology was the most frequent specialty of respondents (45%), treating an average of 35 patients each at the time of the survey
- 12% of the respondents were nurses, treating an average of 167 patients each at the time of the survey

Table 1. Survey respondent demographics and estimated number of centres per country

Country	Number of survey respondents, n (%)	Estimated number of centres, ^a n (%)
Belgium	12 (10.1)	4 (6.9)
Croatia	8 (6.7)	2 (3.4)
Denmark	6 (5.0)	3 (5.2)
France	21 (17.6)	10 (17.2)
Italy	15 (12.6)	7 (12.1)
Norway	7 (5.9)	5 (8.6)
Poland	9 (7.6)	7 (12.1)
Portugal	5 (4.2)	2 (3.4)
Romania	2 (1.7)	2 (3.4)
Spain	16 (13.4)	7 (12.1)
Switzerland	3 (2.5)	2 (3.4)
UK	15 (12.6)	7 (12.1)
Total: 12	119	58

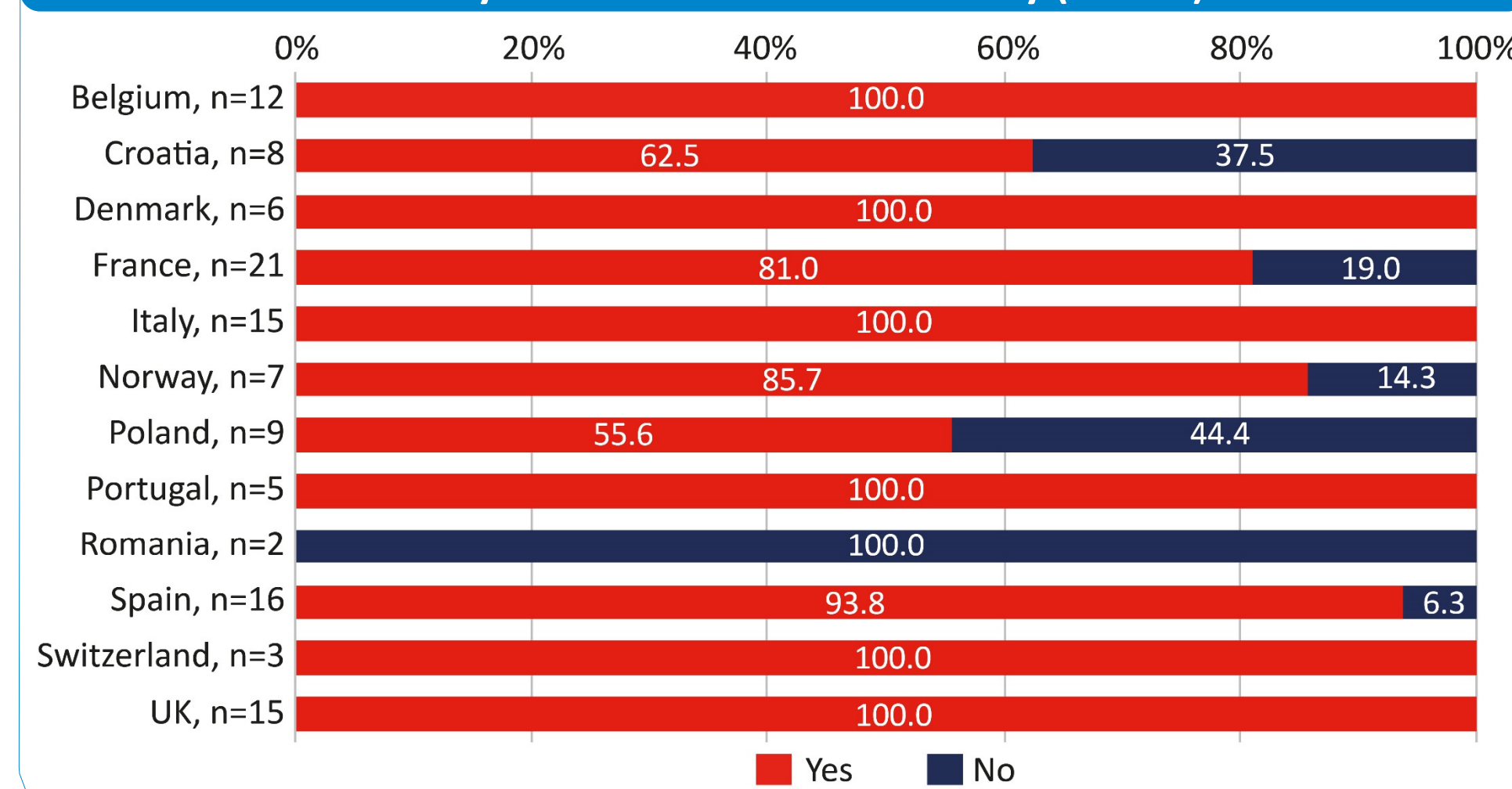
^a Estimation based on email addresses of individuals directly contacting the study team regarding survey completion (N=79)

Availability of routine HPN

87% of HCPs responded that adult patients with chronic IF routinely received HPN in their country (N=119)

- Most HCPs from 11 countries considered that adult patients with chronic IF routinely received HPN in their country, including all HCPs from Belgium, Denmark, Italy, Portugal, Switzerland and the UK (Figure 1)
- Neither of the two HCPs from Romania felt that routine HPN was available to adult patients with chronic IF in their country (Figure 1)

Figure 1. Proportion of HCPs by country with adult patients with chronic IF who routinely receive HPN in their country (N=119)



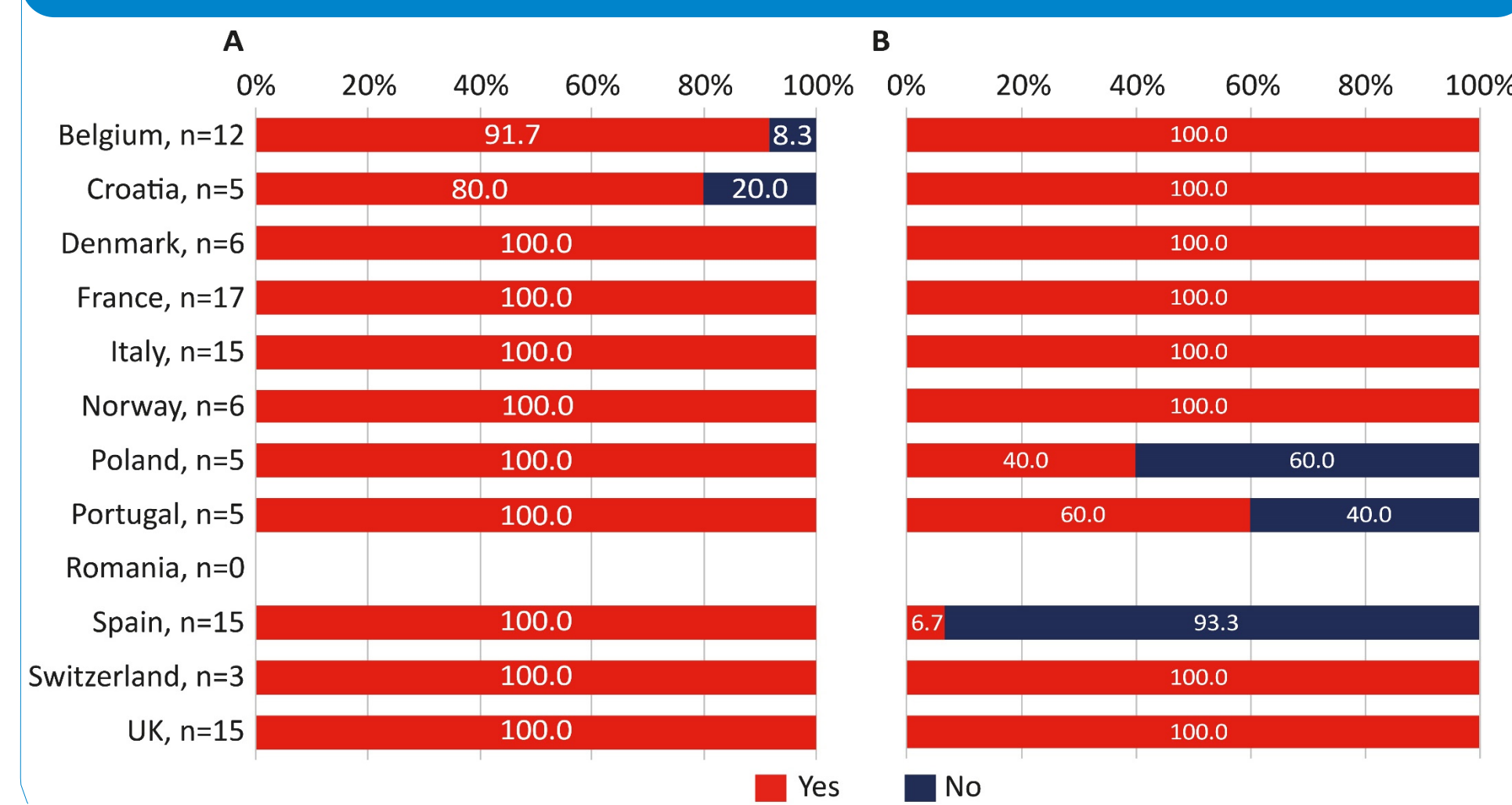
HCPs reported that training on administration of HPN (98%) and home nursing care (HNC) (82%) was available for adult patients with chronic IF (N=104)

- Training on HPN administration:** considered available by the majority (≥80%) of HCPs from 11 countries (Figure 2A), including all HCPs from Denmark, France, Italy, Norway, Poland, Portugal, Spain, Switzerland and the UK (Figure 2A)
- HNC:** considered available by the majority (≥60%) of HCPs from nine countries (Figure 2B), including all HCPs from Belgium, Croatia, Denmark, France, Italy, Norway, Switzerland and UK (Figure 2B)

Costs of HPN (97%) and HNC (96%) were paid mainly by national healthcare systems according to HCPs (n=85)

- For most (>91%) HCPs, HNC was paid for by national healthcare systems, including all from Croatia, Denmark, Norway, Poland, Portugal, Spain, Switzerland and UK

Figure 2. Proportion of HCPs by country with A) training on HPN administration and B) HNC for HPN administration provided for adult patients with chronic IF (N=104)



Transferring patients to an HPN setting

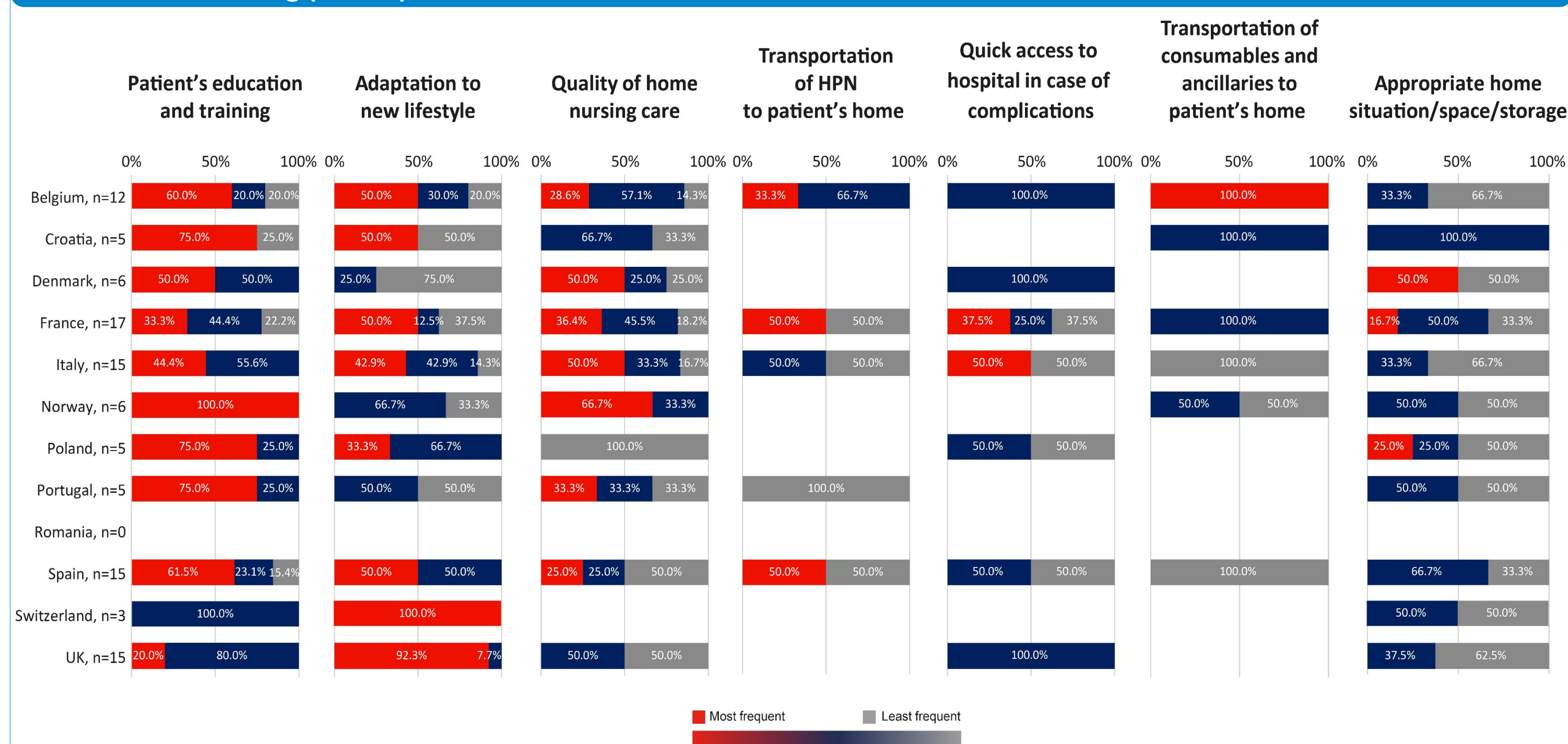
Overall, the most common challenges for transferring patients to a HPN setting were education and training (52%), new lifestyle adaptation (52%) and HNC quality (33%) (N=104) (Figure 4)

- HCPs in different countries experienced different challenges, as shown in Figure 3
- The most frequent challenges experienced by all HCPs in a single country were:
 - Patient education and training (Norway)
 - Adaptation to new lifestyle (Switzerland)
 - Transportation of consumables and ancillaries to patient's home (Belgium)
- The least frequent challenges experienced by all HCPs in a single country were:
 - Quality of HNC (Poland)
 - Transportation of HPN to patient's home (Portugal)
 - Transportation of consumables and ancillaries to patient's home (Italy, Spain)

HCPs indicated that HPN was delivered mostly by the hospital (39%) or homecare companies (38%); homecare companies were the main providers of HPN-related consumables (40%), ancillary (46%) and larger equipment (46%) (N=104)

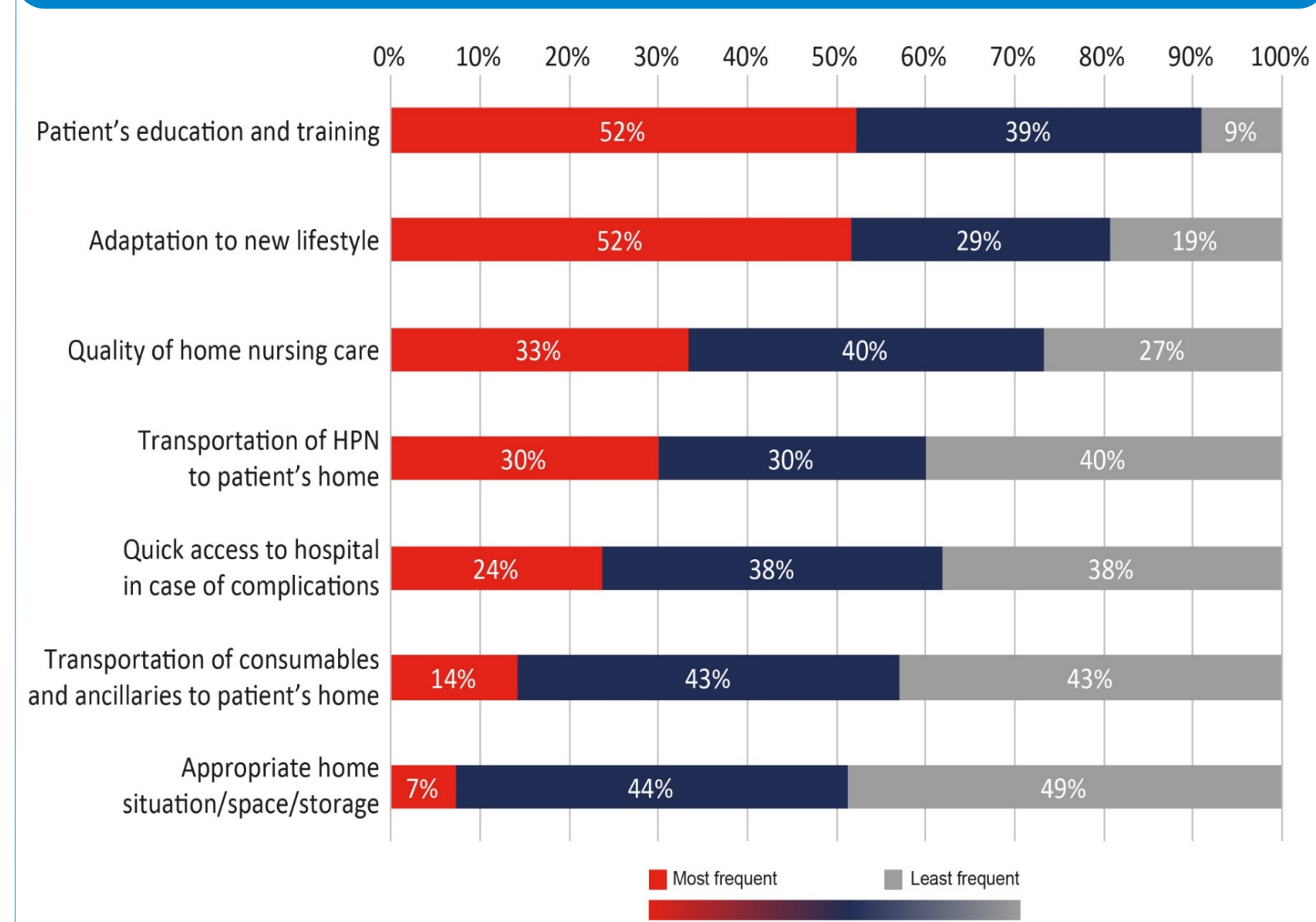
- As expected, there was some variation across countries in who delivered HPN and its related consumables, ancillary and larger equipment (Figure 5)
 - In the UK, only homecare companies were involved
 - In Switzerland, homecare companies and patients/caregivers were involved
 - In France, homecare companies and hospitals were involved
 - Across all other countries, there was variation in the provision of HPN

Figure 3. The proportion of HCPs by country^a reporting the most common challenges when transferring patients to the HPN setting (N=104)



^a In those countries with no data, HCPs did not report the respective challenge as common

Figure 4. The proportion of HCPs reporting the most common challenges when transferring patients to the HPN setting (N=104)



Patients not routinely receiving HPN

The most frequent reasons given for patients not routinely receiving HPN were patient non-compliance (53%), inability to perform HPN tasks (44%), inappropriate social/housing situation (43%) and HPN unavailable (33%)

- The most frequent reasons reported by all HCPs in a single country were (Figure 6):
 - HPN is not available (Portugal)
 - Social and housing situation is not appropriate (Romania)
 - Patient is not compliant (Norway, Romania)
 - Patient unable to perform tasks related to HPN (Croatia, Portugal)
 - Patient is elderly and has no support network (Italy)
 - Patient prefers receiving treatment in hospital (Poland)
- The least frequent reasons reported by all HCPs in a single country were:
 - HPN is not reimbursed (Romania)
 - Patient is elderly and has no support network (France, Portugal)
 - Patient prefers receiving treatment in hospital (Portugal, Romania, Spain)
 - Psychological disorders/drug addiction/abuse of line (Portugal, Spain)

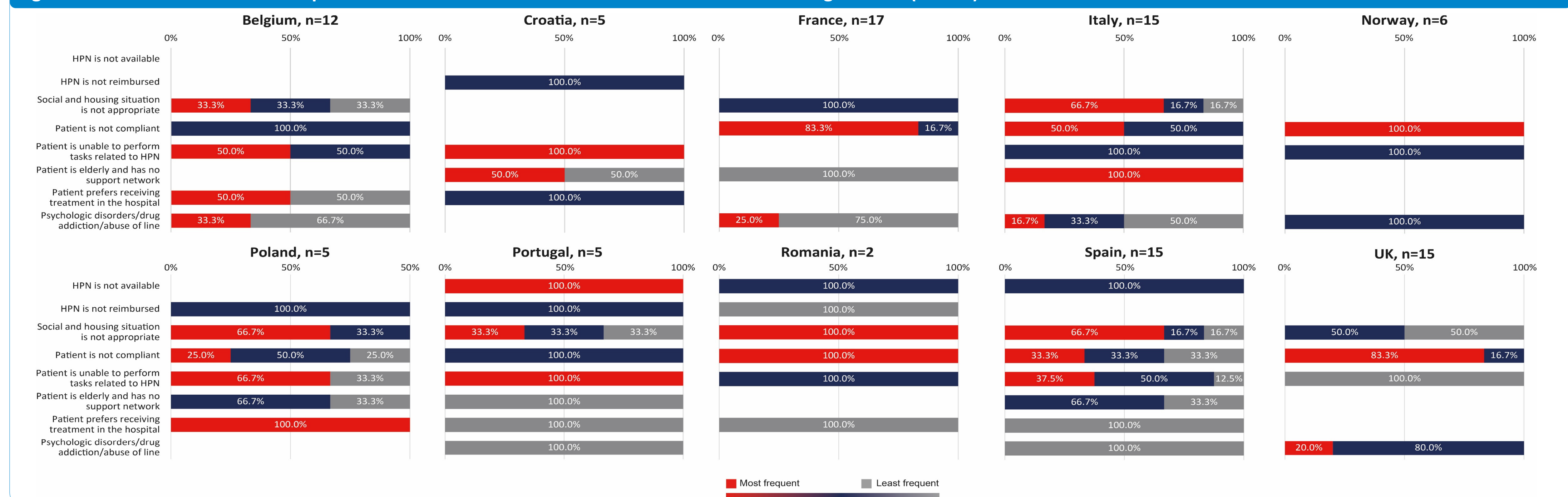
Limitations and Strengths

Limitations

This study is limited by the cross-sectional survey methodology, whereby a physician reports their experiences and perceptions at a single time point only. There is a potential selection bias

- HCPs recruited for the study were recognised for their involvement in chronic IF and often worked in chronic IF centres of excellence

Figure 6. The main reasons adult patients with stable chronic IF do not receive HPN according to HCPs (N=104)



- HCPs who treat chronic IF outside of these centres of excellence may be under-represented

The scope of the study covers 12 European countries only, and therefore cannot be generalised to countries that were not considered part of this study

Strengths

- This is the first study of its kind to investigate the SoC for adults with chronic IF across multiple European countries
- ~30 HCPs had direct input into the survey design through qualitative preliminary assessment
- HCPs from participating countries came from different specialties
- HCPs perspectives on the unmet needs and treatment challenges in chronic IF, were also captured in this study

Conclusions

- Most adult patients with chronic IF can receive HPN, training on administration, or HNC in their country**
- Training, quality of HNC, patient compliance and adaptation to a new lifestyle were identified as key challenges in patient transfer to a HPN setting and might be addressed through improvements in patient management**
- Although training on administration of HPN was mostly reported as being available to patients, it was still identified as a challenge when transferring patients from the hospital to the HPN setting. Further investigations could provide information on how to address this challenge**

Further Atlas of Variance data are presented at this congress on posters P268: "Awareness of chronic intestinal failure versus chronic kidney failure and key areas for improving care delivery to patients with chronic intestinal failure" and P284: "Healthcare professionals' perception of key care delivery goals in patients with chronic intestinal failure in Europe"

Disclosures

This study was sponsored by Takeda Pharmaceuticals International AG. Medical writing support was provided by Sarah Bailey at Parexel International, funded by Takeda Pharmaceuticals International AG. S Lal: Consultant: Baxter, Takeda, VectivBio, Zealand Pharma; Speaker Bureau: Baxter, Takeda, VectivBio, Zealand Pharma; Research Support: Takeda. S Schneider: Grant/Research Support: B Braun, Takeda, VectivBio, Zealand Pharma; Consultant: Axium mTech, Baxter, Nestlé Health Science, Takeda; Speaker Bureau: Biocodex, Fresenius-Kabi, Laboratoires Grand Fontaine, Nestlé Health Science, Takeda, Theradial. P Geransar: Other: Employee: Takeda Pharmaceuticals International AG, owns Takeda stock and has Takeda stock options. E Rzepa: None declared. P Belker Jeppesen: Grant/Research Support: Alkermes A/S, ArTara Therapeutics, Bainan Biotech; Baxter, Coloplast, Ferring, Fresenius Kabi, GlyPharma, Naia Pharma, Novo Nordisk Foundation, NPS Pharmaceuticals, Protara, Shire, Takeda, Therachon, VectivBio, Zealand Pharma; Consultant: Alkermes A/S, ArTara Therapeutics, Bainan Biotech; Baxter, Coloplast, Ferring, Fresenius Kabi, GlyPharma, Naia Pharma, Novo Nordisk Foundation, NPS Pharmaceuticals, Protara, Shire, Takeda, Therachon, VectivBio, Zealand Pharma. L Pironi: Consultant: Baxter, Takeda; Speaker Bureau: Baxter, Takeda

This poster is intended for healthcare professionals only

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Acknowledgements

Special thanks to Andrew Worsfold for his contributions into the overall study design and development of the survey questionnaire, and Caterina Hatzifoti for her significant input at the concept stage of the study

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