

Symptom burden in Immune Thrombocytopenia (ITP): Findings reported by UK patients and physicians from the ITP World Impact Survey (I-WISH)

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INTRODUCTION

- Immune Thrombocytopenia is an autoimmune disease which leads to a shortage of platelets and affects up to 4,000 patients in the UK¹
- ITP is associated with a considerable clinical, humanistic and economic burden²
- While the more serious symptoms of ITP are well reported in ITP, there are limited data on the other symptoms experienced by ITP pts in the UK and how this is reported by treating physicians.
- The I-WISH study aims to understand the frequency and severity of symptoms reported by ITP pts and treaters

AIMS & METHODS

- The ITP World Impact Survey (I-WISH) is a cross-sectional survey of ITP patients and treating haematologists across thirteen countries. Overall, 1507 patients and 472 physicians participated in the study between December 2017 and August 2018
- Patients were recruited via both the ITP Support Association UK and by treating physicians. Eligible patients were aged 18 or over at point of data capture and were diagnosed with ITP
- Patients were asked to select symptoms (from a pre-coded list of 16 symptoms) which they experienced at diagnosis and at the point of data capture. Of symptoms experienced at the point of data capture, patients rated the severity on the 1-7 scale where 7 = 'worst imaginable'.
- As physicians were expected to see most/all symptoms across their ITP caseload, physicians instead reported (from a pre-coded list of 17 symptoms) the **top five symptoms most commonly reported by patients** overall and at diagnosis, and rated all symptoms on their impact on quality of life (QoL) in ITP patients on a 1-7 scale where 7 = 'a great deal'. Scores of 5-7 were combined to indicate high severity
- A steering committee of expert physicians and patient advocacy ITP specialists designed and endorsed the survey materials
- Here we present data from UK patients and physicians

RESULTS

Demographics

- 31 physicians and 120 patients participated in the UK. Mean (SD) patient age was 55 (14.17) years and over two thirds of patients were female (68%)
- On average, patients reported to having been diagnosed for 11.4 (10.25) years
- Over two thirds (68%) of patients reported their current health state to be ≥ 5 using a 7-point Likert scale (7 is excellent health)
- Physicians were primarily specialised in either haematology or haematology-oncology and had reported a mean ITP caseload of 47.5 (39.22). The majority of physicians were based in university/teaching hospitals (77%) versus regional/community hospitals (23%)
- Patient and physician demographics are summarised in **table 1**

Table 1. Respondent demographics

Patient Demographics	Patients (n=120)
Age, mean (SD)	55.0 (14.17)
Gender: female, n (%)	81 (68)
Years since diagnosis, mean (SD)	11.4 (10.25)
Self-reported current health state (7 is excellent health)	
Score of 1-3, n (%)	11 (9)
Score of 4, n (%)	27 (23)
Score of 5-7, n (%)	81 (68)
Physician Demographics	Physicians (n=31)
Primary specialty	
Haematology, n (%)	27 (87)
Haematology-Oncology, n (%)	4 (13)
Current ITP caseload, mean (SD)	47.5 (39.22)
Primary setting	
University/Teaching hospital	24 (77)
Regional/Community hospital	7 (23)

Figure 1. Patient- and physician-reported symptoms at diagnosis

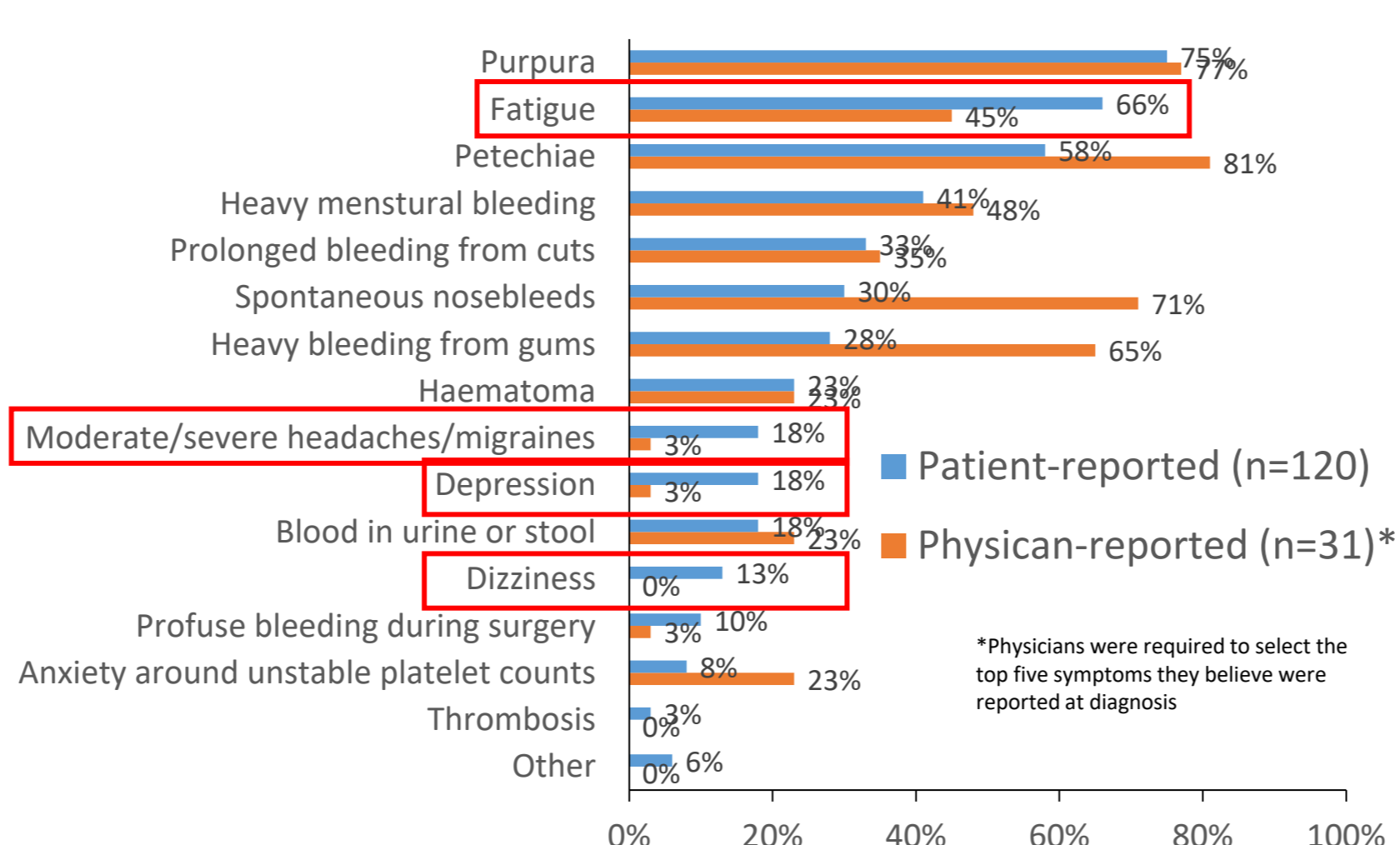
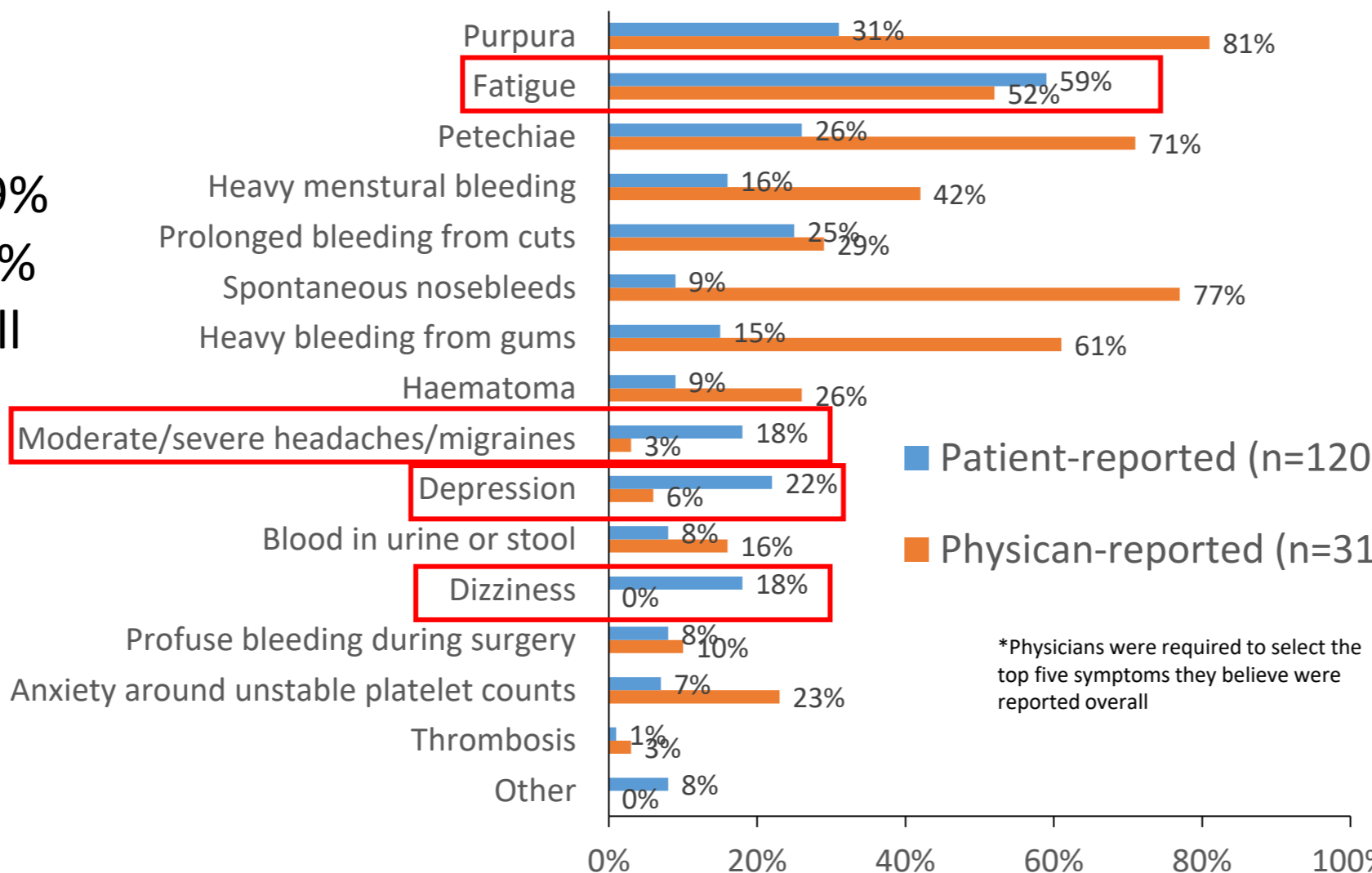


Figure 2. Patient- and physician-reported symptoms at data capture/overall



ITP symptoms experienced at diagnosis

- At diagnosis, two thirds (66%) of patients reported that they experienced fatigue, while less than half (45%) of physicians reported fatigue to be in the top five most reported symptoms at diagnosis
- Notable disconnects in the reporting of symptoms at diagnosis between patients and physicians were also observed in moderate/severe headaches/migraines (18% patients vs. 3% physicians), depression (18% patients vs. 3% physicians) and dizziness (13% patients vs. 0% physicians) (**figure 1**)

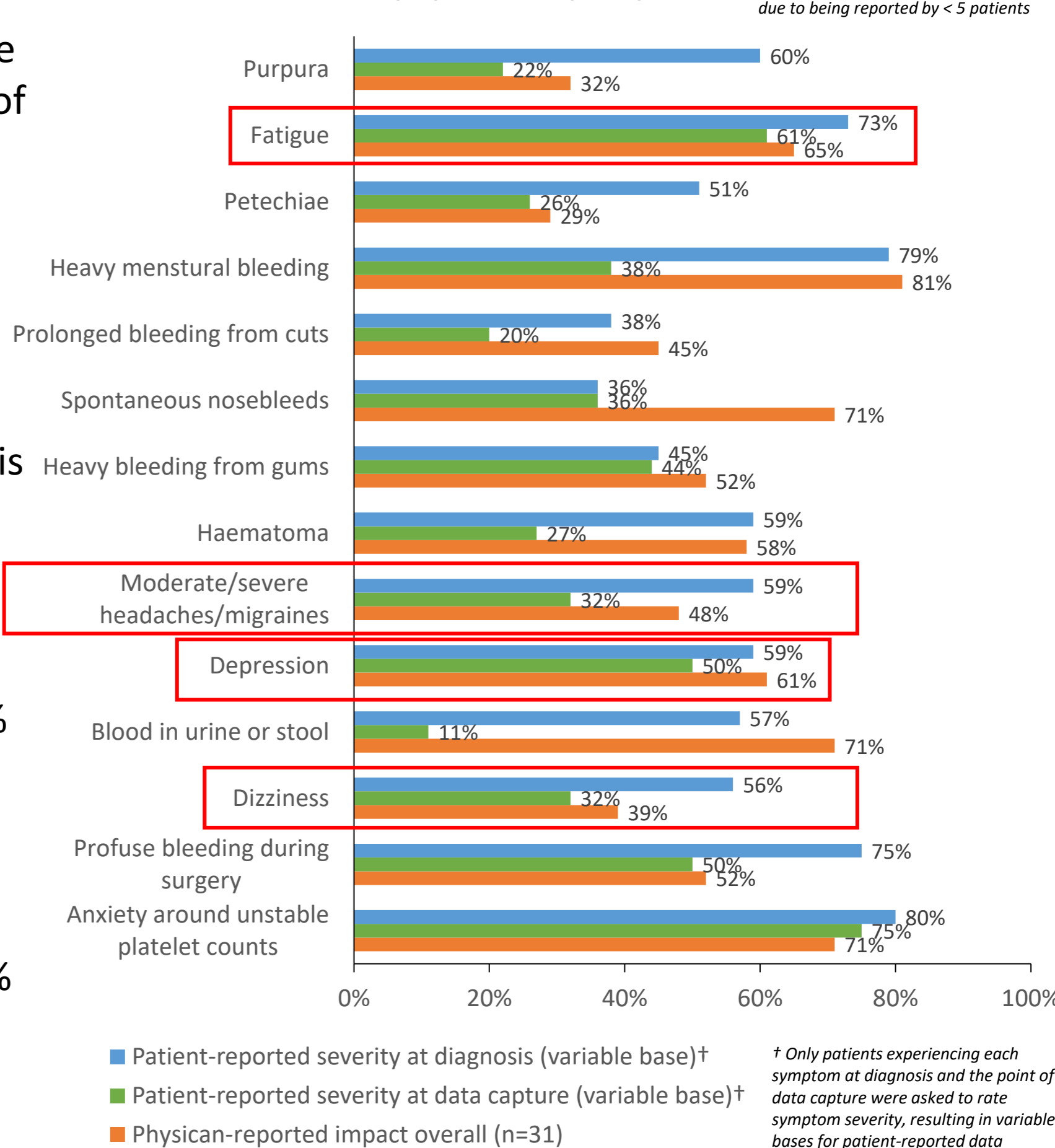
ITP symptoms experienced at data capture and overall

- A similar proportion of patients and physicians reported fatigue as a general symptom of ITP, with 59% patients reporting to experience it 'currently', and 52% physicians including in their top five symptoms overall
- As in the case of symptoms experienced at diagnosis, differences were observed between patients and physicians regarding headaches/migraines (18% in patients vs. 3% of physicians), depression (22% in patients vs. 6% of physicians) and dizziness (18% patients vs. 0% physicians)

Symptom severity and impact on quality of life

- The proportion of patients reporting high severity (rating of 5-7 where 7 = worst imaginable) of fatigue dropped slightly from diagnosis (74%) to the point of data capture (61%). This was generally aligned with the physicians' perception of how fatigue impacts patients' QoL (65% rating high impact)
- Over half (59%) of patients experiencing headaches/migraines at diagnosis reported a high severity, dropping to 32% at the point of data capture. Just under half (48%) physicians believe this symptom to have a high negative impact on QoL
- Patients and physicians are well aligned on the severity and impact of depression in relation to ITP. 59% of patients who experienced depression at diagnosis indicated a high severity, dropping to 50% of patients at data capture. 61% of physicians indicated a high impact of depression on patients' QoL
- Of patients who experienced dizziness at diagnosis, 57% reported a high severity, which reduced to 33% at data capture. 38% of physicians believe dizziness to highly impact patients' QoL (**figure 3**)

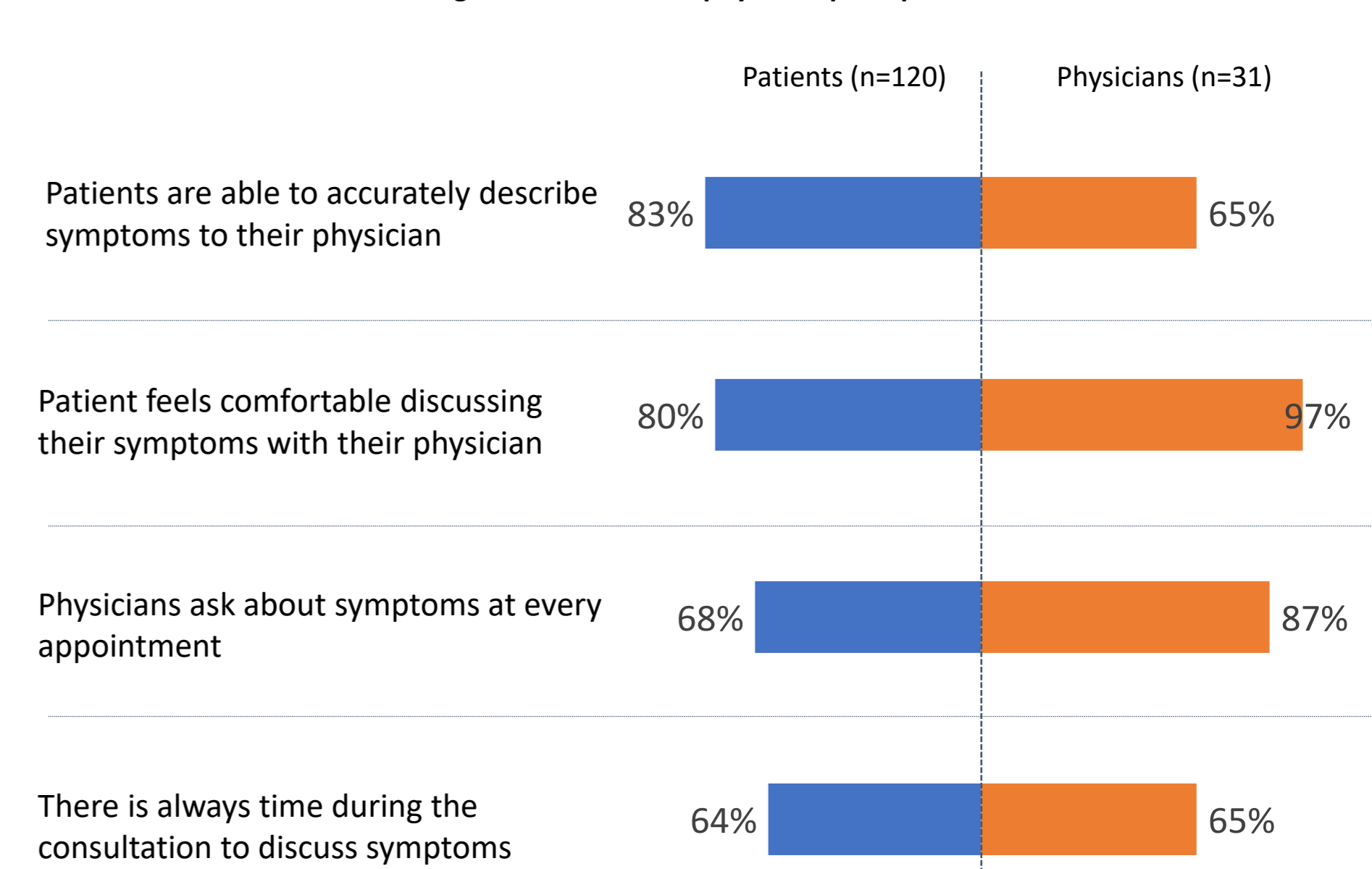
Figure 3. Patient-reported symptom severity at diagnosis and point of data capture and physician-perceived overall impact on symptoms on quality of life



Pt-HCP communication about symptoms

- While the vast majority (87%) of physicians reported to ask patients about their symptoms at every appointment, this was lower in patients (68%), suggesting some disconnect with regard to how symptoms are communicated
- Two third of patients and physicians agreed that there is always time to discuss symptoms during consultations, indicating alignment between patients and physicians. However, this indicates up to a third of patients and physicians need more time during consultations to discuss symptoms (**figure 4**)

Figure 4. Patient and physician perceptions on communication



CONCLUSIONS

- Overall, these data indicate a considerable disease burden among ITP patients in the UK, which is only partially improved following ITP diagnosis
- Physicians generally align with patients on the severity of symptoms and how much they impact patients' lives. However, there is a clear disconnect between patients and physicians with regard to the frequency with which these symptoms are experienced both at diagnosis and overall
- Patients indicate slightly less satisfaction than physicians with regard to being able to discuss symptoms during consultations, suggesting there remains an unmet need in the management of ITP and the communication between patients and physicians

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