

# Worldwide experiences and unmet needs of patients with chronic spontaneous urticaria and treating physicians: The Urticaria Voices study

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## CONCLUSIONS

- Globally, the reported time to CSU diagnosis varies between patients and physicians, indicating a discrepancy in their perspectives
- Patients with CSU report a prolonged disease journey involving consultations with multiple physicians before and after the diagnosis of CSU, the frequency of consultations was under-estimated by physicians
- Patients switched their physicians to find a CSU specialised physician, more effective treatments and better symptom control, however the majority of patients remained uncontrolled on current treatment
- Physicians and patients were aligned on the unmet needs; more knowledge on CSU, better information regarding treatments, and better access to treatments were the mostly reported unmet needs by the physicians and patients

## INTRODUCTION

- Chronic spontaneous urticaria (CSU) is characterised by the occurrence of itchy wheals (hives) and/or angioedema for more than 6 weeks and can have a major impact on patients' well-being<sup>1</sup>
- Second-generation H1-antihistamines (H1-AH) are first-line treatment for CSU, up-dosed to 4 times the standard dose if needed.<sup>2</sup> However, approximately 50% of patients have uncontrolled disease despite treatment with H1-AH<sup>3</sup>
- The Urticaria Voices study aimed to assess perceptions of patients with CSU and physicians treating CSU on various aspects of disease management

## RESULTS

- Overall, 582 patients with CSU (women, 62%; age [mean±SD] 42.2±11.9 years) and 862 physicians participated in the study; Patients had a disease duration of (mean±SD) 9.2±10.3 years

### Patient experiences of living with CSU and physicians' perceptions of CSU

- Globally, patients reported a delay of (mean±SD) 2.0±5.4 years from the onset of first symptoms to receiving a diagnosis for their CSU (7.1±8.5 years) whereas physicians estimated a delay of (mean±SD) 0.9±1.1 years (Table 1)

**Table 1. Patient- and physician-reported disease characteristics of CSU in the Urticaria Voices study**

	Patients with CSU <sup>a</sup>							
	Global (N=582)	US (N=152)	Canada (N=73)	France (N=86)	Germany (N=79)	Italy (N=64)	Japan (N=41)	UK (N=87)
Delay between symptom onset and diagnosis, years	2.0±5.4	1.6±5.3	3.0±5.8	2.4±5.5	1.2±1.4	1.7±6.8	2.3±7.1	2.1±5.5
Current concomitant treatments	2.9±2.6	2.8±1.9	2.0±1.3	1.9±1.7	5.0±4.6	2.1±1.3	1.6±1.1	3.8±2.5
	Patients with CSU <sup>a</sup> currently on H1-AH							
	Global (N=460)	US (N=115)	Canada (N=54)	France (N=63)	Germany (N=65)	Italy (N=53)	Japan (N=33)	UK (N=77)
Urticaria control n (%) <sup>b</sup>								
Inadequately controlled (UCT score <12)	386 (84)	98 (85)	37 (69)	55 (87)	58 (89)	48 (91)	24 (73)	66 (86)
	Physicians' perceptions of CSU							
	Global (N=862)	US (N=265)	Canada (N=40)	France (N=59)	Germany (N=114)	Italy (N=209)	Japan (N=98)	UK (N=74)
Time to confirmed diagnosis	0.9±1.1	0.8±0.8	0.9±0.7	1.2±1.2	0.7±0.7	1.2±1.3	0.8±1.2	1.1±1.7
Urticaria control (%) <sup>c</sup>								
Patients on AH that are uncontrolled	33.9	32.8	42.3	30.7	32.8	34.1	33.7	36.5

<sup>a</sup>Includes patients with isolated CSU as well as those with CSU and concomitant CINDU. <sup>b</sup>Patient-reported level of symptom control based on individual and composite UCT scores (PROM) assessed by their physicians over the previous 4 weeks. <sup>c</sup>Level of disease control achieved on patients' current treatment according to physicians' own clinical judgement and last assessment. Data are presented as mean±SD unless specified otherwise. CINDU, chronic inducible urticaria; CSU, chronic spontaneous urticaria; H1-AH, H1-antihistamine; N, number of patients or physicians; n, number of patients with an outcome; SD, standard deviation; UCT, Urticaria Control Test.

## References

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## Disclosures

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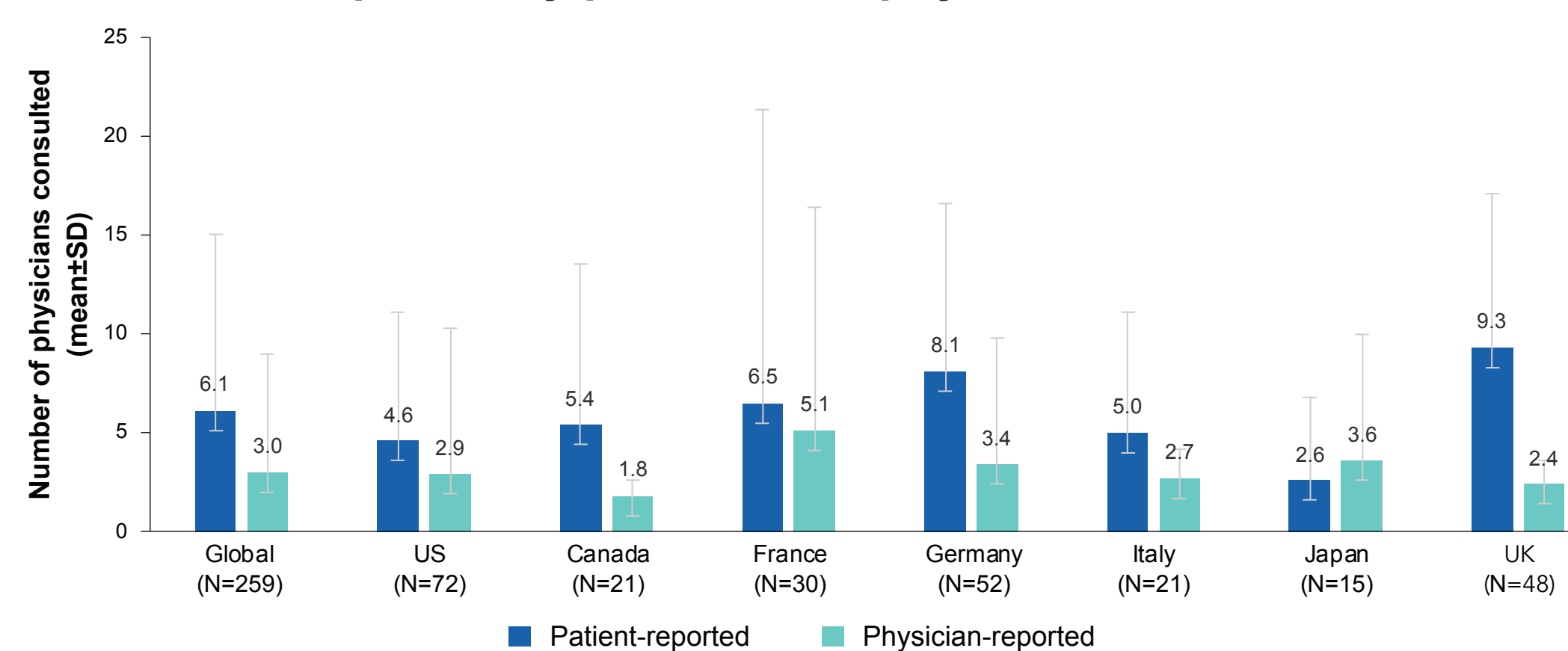
## OBJECTIVE

- Here, we report patients' experiences on living with CSU and the physicians' perceptions of CSU (globally and by country), and unmet needs of both patients and physicians from the global Urticaria Voices study

## METHODS

- Urticaria Voices was designed as a global (US, Canada, France, Germany, Italy, Japan and UK), cross-sectional, online quantitative survey of anonymised patients with CSU and physicians treating CSU, conducted between February 2022 and September 2022
- Eligible adult patients had a self-reported clinician-provided diagnosis of CSU and were currently following a physician-prescribed treatment
- Patients reported taking (mean±SD) 2.9±2.6 concomitant medications for CSU globally (ranging from 1.6±1.1 in Japan to 5.0±4.6 in Germany)
  - Overall, 79% (460/582) reported being on H1-AH, of whom, 84% were inadequately controlled (UCT<12), ranging from 69% in Canada to 91% in Italy
  - Physicians estimated ~34% of their patients on H1-AH were inadequately controlled ranging from 30.7% in France to 42.3% in Canada (Table 1)
- Globally, patients reported consulting (mean±SD) 6.1± 8.9 physicians (multiple specialties) before the diagnosis of CSU (highest in UK, 9.3±7.8 physicians consulted; Figure 1)
- Physicians reported that their patients had consulted (mean±SD) 3.0±6.0 physicians globally (multiple specialties) for the diagnosis of CSU (highest reported in France, 5.1±11.3) resulting in a delay of ~1 year in reaching a diagnosis (Figure 1)

**Figure 1. Mean number of physicians consulted before the diagnosis of CSU, self-reported by patients and physicians**

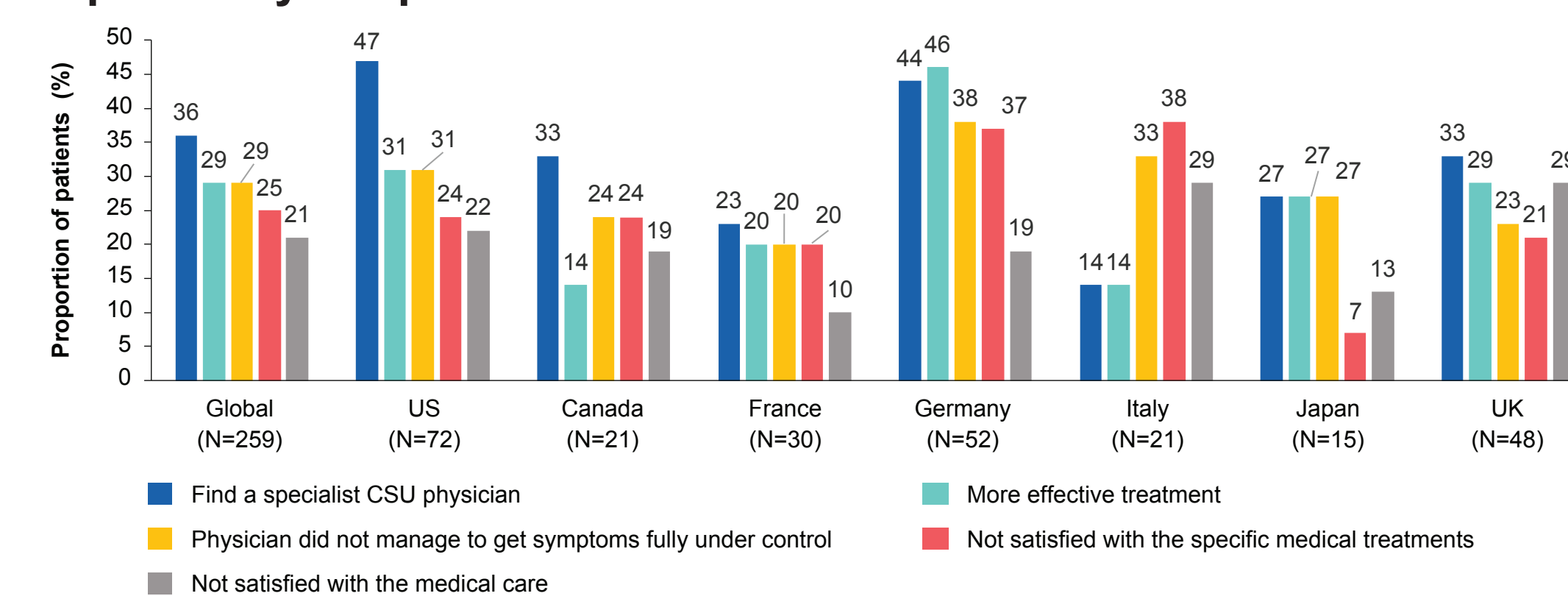


<sup>a</sup>Based on survey question: "How many different physicians within each specialty (regardless of type) have you seen before your diagnosis was confirmed?". <sup>b</sup>Based on survey question: "To the best of your knowledge, can you please estimate the mean number of different individual specialists including yourself that your patients with CSU see before their diagnosis is confirmed?" CSU, chronic spontaneous urticaria; UK, United Kingdom; US, United States.

- In addition, patients reported switching their main physicians (mean±SD) 2.6±2.7 times globally after the diagnosis of CSU (US: 2.8±3.0; Canada: 2.3±1.4; France: 2.3±2.1; Germany: 2.6±2.9; Italy: 1.7±1.0; Japan: 3.7±4.9; and UK: 2.5±2.1)
- Globally, the primary reasons for patients switching their physicians were:
  - to find a specialist CSU physician (36% [94/259]),
  - for more effective treatment (29% [76/259]), and
  - physician did not manage to get symptoms fully under control (29% [75/259]; Figure 2)

- Patients completed an electronically signed informed consent (IC) before they completed a 40-minute online survey, which comprised of questions on socio-demographics, Urticaria Control Test (UCT), and treatments received (duration of treatment was not recorded); physicians e-signed the IC and completed a 30-minute internet-based survey, which comprised of questions on treatment and disease management. No patient identifiers were collected
- Patients who were recruited from the general population panel were remunerated according to the fair market value, while those recruited via patient advocacy groups were not
- Data by responder type were analysed descriptively

**Figure 2. The primary reasons for patients switching their physicians, reported by the patients**

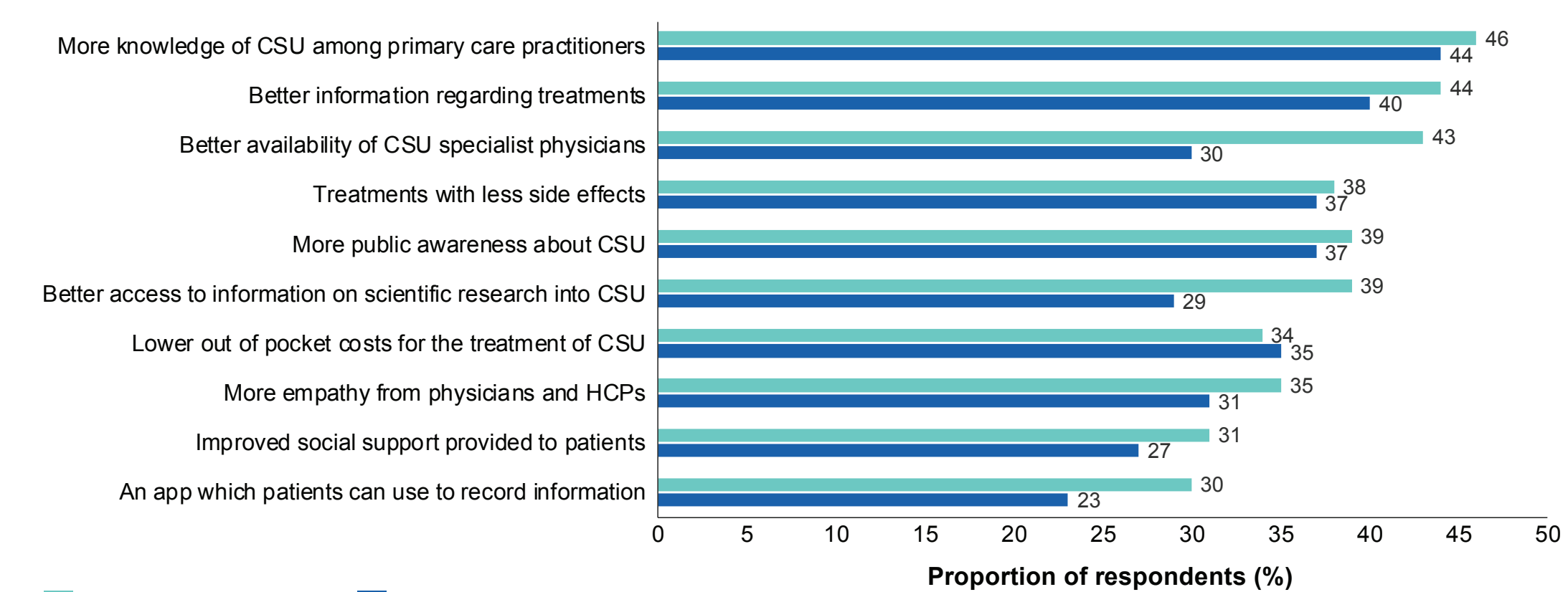


CSU, chronic spontaneous urticaria; UK, United Kingdom; US, United States.

## Unmet needs of patients with CSU and treating physicians

- For both patients and physicians, the need for more knowledge on CSU, better information regarding treatments, better access to treatments, and treatments with less side effects were the top unmet needs (Figure 3)

**Figure 3. Patients' and physicians' hierarchy of unmet needs from the Urticaria Voices study**



CSU, chronic spontaneous urticaria; HCPs, health care professionals.

## Strengths and limitations

- This multinational, real-world evidence study with large sample size supported generalisability of the results among patients primarily on AH. However, online surveys are limited to patients who have access to internet and are subjected to a recollection bias. The patient and physician populations were not matched (physicians surveyed were not treating the patients surveyed)

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