# Understanding the impact of Chronic Spontaneous Urticaria (CSU) and what is most important to patients – Results from qualitative patient interviews

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Most commonly allergist (USA),

Diagnosis

dermatologist (EU)

manage/

educate

## Background

- With new injectable biologic treatments planned to launch in chronic spontaneous urticaria (CSU) it is important to capture, in a structured manner, patient preferences for different treatments profiles
- Patient preference studies are a means of generating data on patients' perception of existing or new treatments<sup>1</sup> and can be beneficial in informing reimbursement/market access discussions<sup>2,3</sup>
- Here we present the results of the qualitative phase of the CHOICE study conducted in order to inform the discrete choice design of the quantitative phase

# **Objective**

 To understand the patient view on disease and its impact, knowledge and expectations related to treatments among patients with CSU in USA, Germany and Spain

## Methods

- Telephone interviews (~45 minutes) were conducted with patients diagnosed with CSU who were recruited via physician referral in the USA, Germany and via a patient panel in Spain
- The interview focused on areas such as:
  - Physical and emotional impact
  - Perception/knowledge of CSU
  - Patient journey
  - Treatment experience and expectations from future treatments
- Inclusion: CSU patients inadequately controlled on H1 antihistamines despite up-dosing and eligible for a biologic
- Exclusion: Less than 1 year since confirmed medical diagnosis of CSU
- Country-specific and pooled content thematic analysis was conducted
- Results are presented for the pooled cohort

#### Results

- The cohort comprised 30 patients (10 per country) described in Table 1
- Most commonly reported comorbidities were anxiety/depression (30%), sleep disturbance (23%) and allergies (20%) (Figure 1)

**Table 1: Patient demographics** 

Sudden onset

overwhelmed,

scared, confused

Feeling

1<sup>st</sup> present to different HCPs: GP,

Dermatologist, Allergist, ER etc.

	Total cohort (N=30)
Mean (SD) age, years	42 (15)
% Female	77%
CSU severity	
Moderate, n (%)	15 (50%)
Severe, n (%)	15 (50%)
Mean (SD) time since CSU diagnosis, years	9 (8.9)
Current CSU treatments, n (%)	
Antihistamines	30 (100%)
Omalizumab	16 (53%)
Corticosteroids	14 (47%)
Cyclosporine	2 (7%)
Doxepin	2 (7%)

Figure 2: Patient Journey and experience living with CSU

First signs

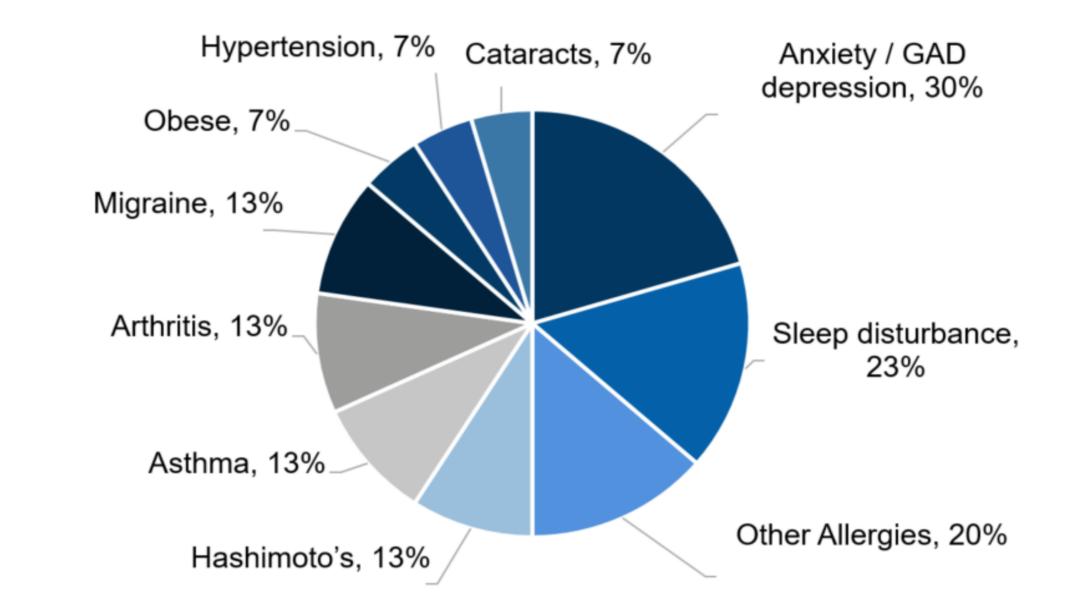
Often self-medicating before

Searching for root cause is a

Seeking advice from friends & colleagues

Searching online to supplement HCP advice

concern for patients



• Figure 2 summarizes the key steps in a patient journey and patient experience

### Physical and emotional impact

ollow-up

Recurring

Outbreak

**Treatment** 

• Patients will try anything for relief:

Delayed access to biologics

Creams, natural remedies, diet, avoiding toxins

Figure 1: Comorbidities

- The unpredictability of the symptoms and uncertainty around the duration of disease were consistently reported
- Itching intensity, swelling, soreness were high but variable over time

Living with CSU

Feeling of constant threat of

Stress from unpredictability

Strong mental burden

Need relief / freedom

outbreaks

- The emotional burden was high at disease onset and worsening over time
- Patients reported inability to function normally, their social and personal life was highly impacted

#### Perception/knowledge of CSU

- There was variability in the level of knowledge of CSU, patients rely on information from their physician and online sources
- Patients felt a strong need to understand their condition further and seek ways to manage their condition and identify potential triggers

#### Treatment experience and expectations from future treatments

- There was a feeling of dependency on medication and high daily pill burden was a problem
- Patients were desperate for complete relief and considered this a key outcome for future treatments
- Most patients would accept mild short-term downsides for high efficacy and long-term symptom-free periods

### Conclusions

- This study highlights the complex impact of CSU and reveals expectations that patients have from treatments
- The data will be used to design a discrete choice experiment to assess in a quantitative way preferences for treatment profiles which could support future HTA assessment of new drugs in CSU

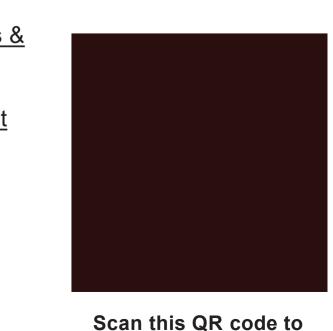
#### References

- Jackson Y et al (2019). Expert Review of Pharmacoeconomics & Outcomes Research, 19:4, 383-396.
- Bouvy J.C et al (2020). Patient, 13(2):145-149.
- Cowie et al (2019). NICE Scientific Report Measuring Patient

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