

Table SI. Sample questions from telephone interviews with patients

Section 1: Personal/family context – Basic demographics and support system

- Tell me about who you live with, who is important in your life, and who provides you with support
- What is a typical day like for you? Do you work, volunteer, participate in groups or activities? Has this changed over the course of living with chronic spontaneous urticaria (CSU)?

Section 2: Disease and treatment history

- How long did it take to arrive at your CSU diagnosis? What was the process you went through to get it? Which healthcare providers (HCPs)/physicians were involved?
- What was your reaction to the diagnosis? What thoughts and emotions did you experience?
- How did you arrive at a treatment plan and what was your involvement in making those decisions?
- What were your expectations of treatment? Have your expectations changed over time?
- How have you felt about your treatment emotionally?

Section 3: Relationship with medical team

- What is your own role in determining your treatment? Are you happy with that role? If not, how would you like it to be different?
- When you have questions or concerns between visits, how do you feel about contacting HCPs/physicians?
- Who else do you turn to with questions?
- Are there areas where you are less satisfied with the care that you receive?

Section 4: Impact of disease and life with CSU

- Can you describe what flares are like and how they affect you? Do they follow a pattern? How frequent are they?
- How has CSU affected you and impacted your life? For example, have you changed your routines or participation in activities? Or has it affected your relationships? Or finances?
- How do you feel about your future with this disease? What impact do you foresee CSU having on your life?

Section 5: Support and resources for managing CSU

- What resources have you used to learn more about CSU in general, your diagnosis, treatment options and living with CSU? For example, have you turned to patient organizations, friends/family, others with similar conditions, the internet?
- Do you feel like you have adequate information? Why/why not? What information is lacking?
- Have you become involved with (online, offline) support groups or other related activities of any kind? What role do these groups play?
- What kind of support is most valuable to you?

The interview guide for use with patients was not intended as a rigid script but as a flexible tool to facilitate conversation. Researchers could adapt their inquiries as the interview evolved, allowing patients to share significant perspectives and insights that the researcher may not have previously contemplated.