Background: Gout is one of the most common forms of inflammatory arthritis in Europe, but awareness of it is relatively low. There is limited information available about the impact of gout on patients, and more generally on society.

Objectives: To give gout patients a voice to better understand the impact that the disease has on their lives.

Methods: From June to September 2018, gout patients from 14 European countries were invited to complete a 15 minutes online survey. Adult (18+) patients diagnosed with gout who met the criteria and finished the survey were included in the analysis. The design and content of the survey has been developed together with several patient and clinical experts to ensure that the most relevant aspects of the disease were covered. The questionnaire was translated into 11 different languages and checked that patient-friendly language was used. Patients were recruited via patient associations, leaflets provided to doctors and consumer online market research panels to reach the targeted number of patients.

Results: 1,100 gout patients completed the survey, 78% of respondents were male and 22% female. The mean age of participating patients was 55 years, 56% were employed or studying. The mean age of patients at diagnosis was 45 years and 38% were diagnosed during their first flare. The patients had on average 2.9 flares per year and the length of their last flare was 5 days on average. 84% of patients experienced moderate to severe pain with their most recent flare, 63% had severe pain with their worst flare ever. Patients reported that gout has a significant impact on their daily activities: on their ability to walk (59%), changes in mood and mental well-being (43%) and difficulties relating to their partner (26%). 27% of patients reported that their self-esteem has dropped.

Convenience (53% of patients), agony (37%) and frustration (32%) were the words patients most often associated with gout. 10% of patients (or a family member) have retired or lost a job because of their gout.

Despite reporting these not insignificant impacts of gout on their lives, 79% of patients said that they are satisfied with their current treatment. However, two-thirds (68%) of younger patients (18-35 years) reported that they are satisfied with their current treatment. 69% of gout patients felt they have an open and trusted relationship with their doctor. But 42% of patients told their doctor about <50% of their flares in the year. Over a quarter of gout patients who have had 5 or more flares feel they are wasting their doctor’s time. 60% of patients said that they know nothing or very little about their condition, and 94% of the patients rated that there is no or very little knowledge amongst the general public about gout.

Conclusion: The results of this survey demonstrate that gout has a significant impact not only on patients, but also on their families and society. Gout seems to lead to stigma and many patients may feel guilty about their lifestyle choices. Actions need to be taken to manage dissatisfaction of patients and to encourage them to speak up to request better management of the disease. There seems to be an urgent need to educate both patients and the general public about the seriousness of gout and the burden on patients and their families. The results of this survey will be used for communication with healthcare professionals to better address patients’ unmet needs.

Acknowledgement: The survey was conducted by Hall & Partners and funded by Grünenthal GmbH.