

Patient perspective on the impact of complex perianal fistulas in Crohn's disease on quality of life: Introducing the concept of the patient survey conducted in Europe

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Background

- Perianal involvement in Crohn's disease (CD), including fistulas, ulcers, abscesses, strictures and cancer, can lead to a significant, occasionally debilitating impairment in the patients' short- and long-term quality of life (QoL)¹
- Perianal fistulas can cause symptoms such as faecal incontinence, rectal pain, swelling and fever, which may significantly affect a patient's social performance, sexual function and normal life activities^{2,3}
- Fistulas are a relatively common CD complication: approximately 35% patients with CD have at ≥ 1 fistula and the majority of CD fistulas are complex^{1,4,5}
- Despite this, few studies have assessed the impact of complex perianal fistulas (CPF) on the QoL of patients with CD from the patient perspective

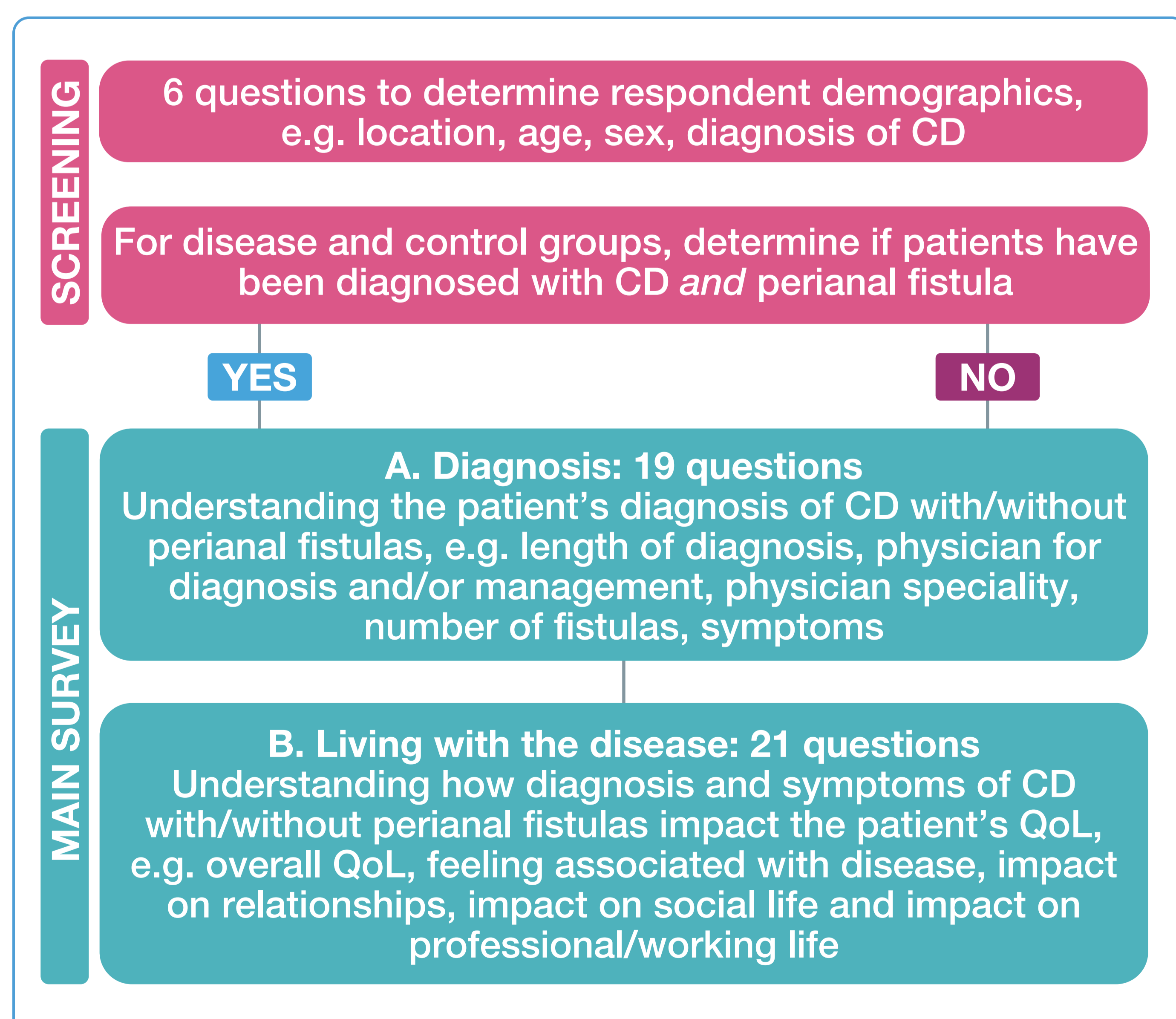
Objective

- This survey aims to assess the impact of perianal fistulas in CD on patients' QoL in Europe

Methods

- A survey assessing the effect of CPF on the QoL of CD patients was developed by patient representatives and medical experts
 - It consisted of questions on patient demographics and questions relating to history and activity of CD with/without CPF, as well as the self-reported impact on QoL, including the impact and restrictions on close relationships and social life, sexual activity, professional life and absence from work (**Fig. 1**)
- The survey was launched online on the European Federation of Crohn's & Ulcerative Colitis Associations' (EFCCA) website on 15 July 2019 and remained open until 31 December 2019
 - The link to the survey was shared to national inflammatory bowel disease patient associations through the EFCCA network
 - Both CD patients with and without CPF were invited to participate in order to create a control group of patients for data analysis
 - The self-selective, anonymous survey was offered in English, French, German, Greek, Hebrew, Italian, Polish, Portuguese, Romanian, Spanish and Slovenian

Figure 1. Survey structure used to assess the impact of perianal fistulas in patients with CD

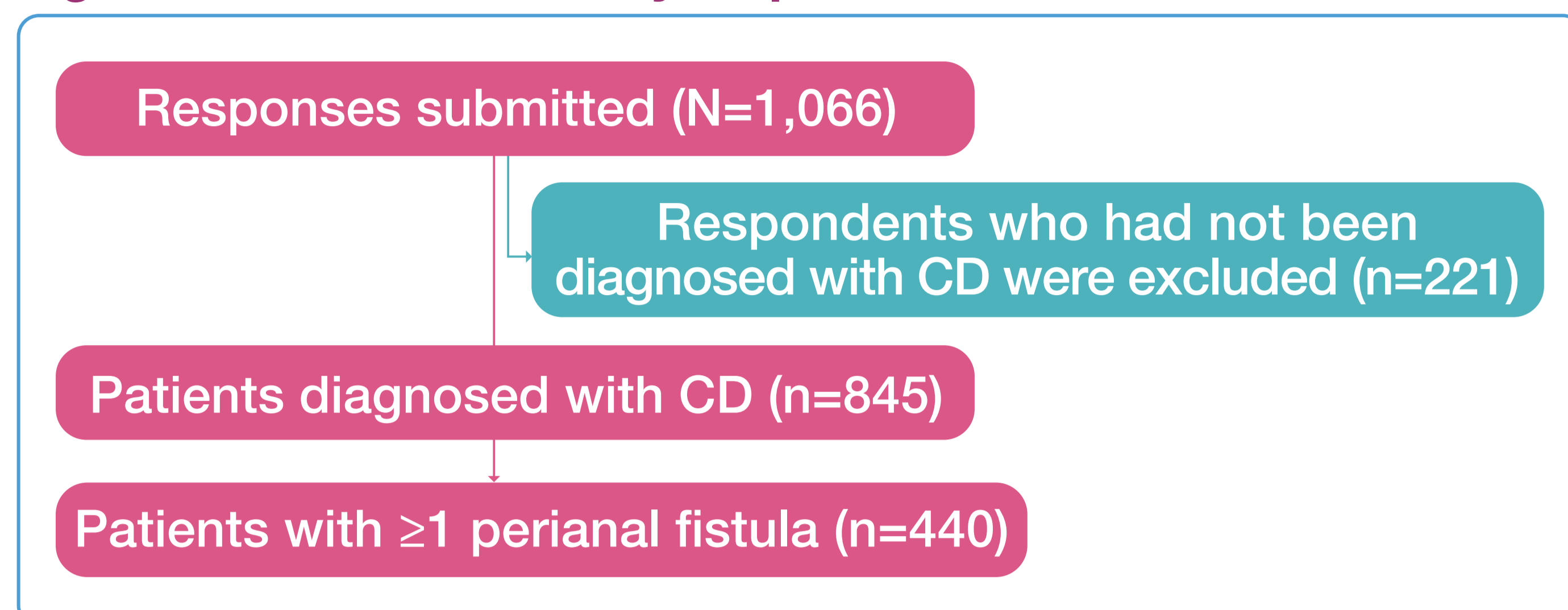


CD, Crohn's disease; QoL, quality of life.

Results

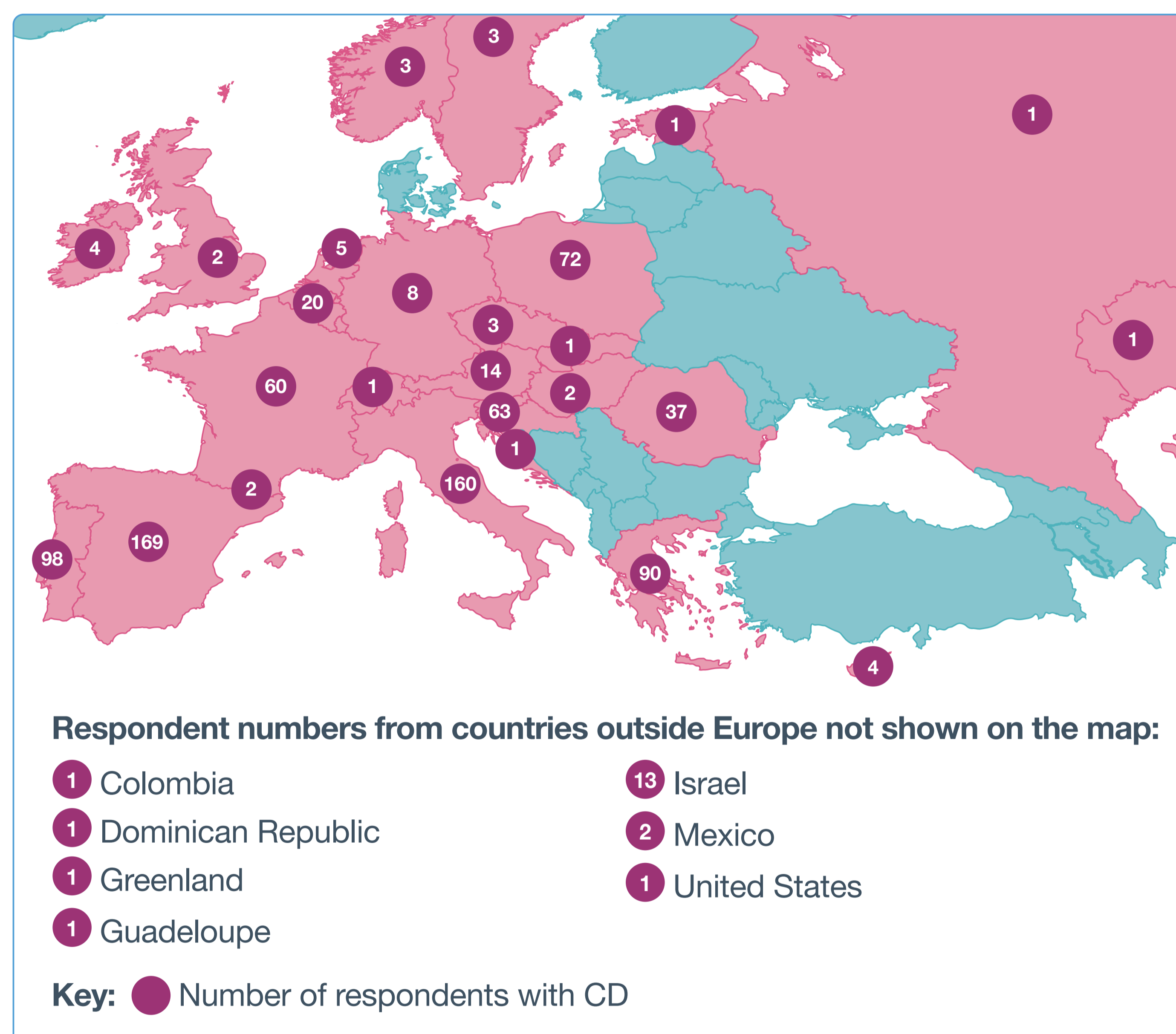
- In total, 845 patients diagnosed with CD participated in the survey (**Fig. 2**) from 33 countries around the world (**Fig. 3**)
 - 66.7% (n=564) patients were female
 - In addition to CD, 52.1% (n=440) of the respondents also suffered from ≥ 1 perianal fistula

Figure 2. Number of survey respondents



CD, Crohn's disease.

Figure 3. Respondent country of residence



CD, Crohn's disease.

Conclusions

- The data collected will allow a comparison between CD patients with/without CPF, and between patients in different countries, in important patient-relevant aspects of QoL assessments
- There are some limitations of the survey:
 - Selection bias may have an impact on the data as the survey is self-selective, and only available online and in a limited number of languages
 - Recall bias may also have affected some responses due to the retrospective nature of a number of questions
- The collected data will be statistically analysed thoroughly in 2020
 - Initial analysis of the survey responses showed that more than half of responders had ≥ 1 perianal fistula
- The results will provide valuable insights and a deeper understanding of the often unspoken burden in the life of patients suffering from CD with CPF, and may potentially aid treatment decisions for these patients

References

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Disclosures

AS has received personal fees from Takeda, Pfizer and Sofar. SL has nothing to disclose. LA has received personal fees from Pfizer. DB was an employee of Takeda at time of abstract submission. She is now an employee of F. Hoffmann-La Roche Ltd.