

# Real-World Evidence Collection in an Online Patient Community to Identify Lifestyle Challenges Considered Most Important to Patients With Chronic Pancreatitis

Yasmin Hernandez-Barco, MD<sup>1</sup>; Samer Al-Kaade, MD<sup>2</sup>; Janine Twal, PharmD<sup>3</sup>; Valerie J. Powell, MS<sup>4</sup>

<sup>1</sup>Massachusetts General Hospital, Boston, MA, USA; <sup>2</sup>Advanced Endoscopy, Mercy Clinic Gastroenterology, St. Louis, MO, USA; <sup>3</sup>Aimmune Therapeutics, a Nestlé Health Science company, Bridgewater Township, NJ, USA; <sup>4</sup>CorEvitas, LLC, Waltham, MA, USA

International Society for  
Pharmacoeconomics and  
Outcomes Research 2023  
May 7–10, 2023  
Boston, MA





## INTRODUCTION

- People with chronic pancreatitis (CP) are at an increased risk of developing exocrine pancreatic insufficiency (EPI) from a lack of or ineffective secretion of innate digestive enzymes, leading to symptoms of maldigestion/malnutrition and reduced quality of life (QoL)<sup>1,2</sup>
- Diagnosis and management of EPI are suboptimal, highlighting the need for increased awareness of EPI in high-risk patients and a better understanding of treatment goals and strategies<sup>2</sup>
- To better understand the impact of EPI, a dual approach using a traditional US-based registry with patients from gastroenterology sites and an online community with patient support and real-world evidence reporting is being implemented
- We describe the collection of patient-reported information from the online community via a survey/research event with a gastroenterologist

## OBJECTIVE

- To better understand CP/EPI and identify symptom control challenges or mental health concerns that members of the online community often face during the holiday season and on a day-to-day basis

## METHODS

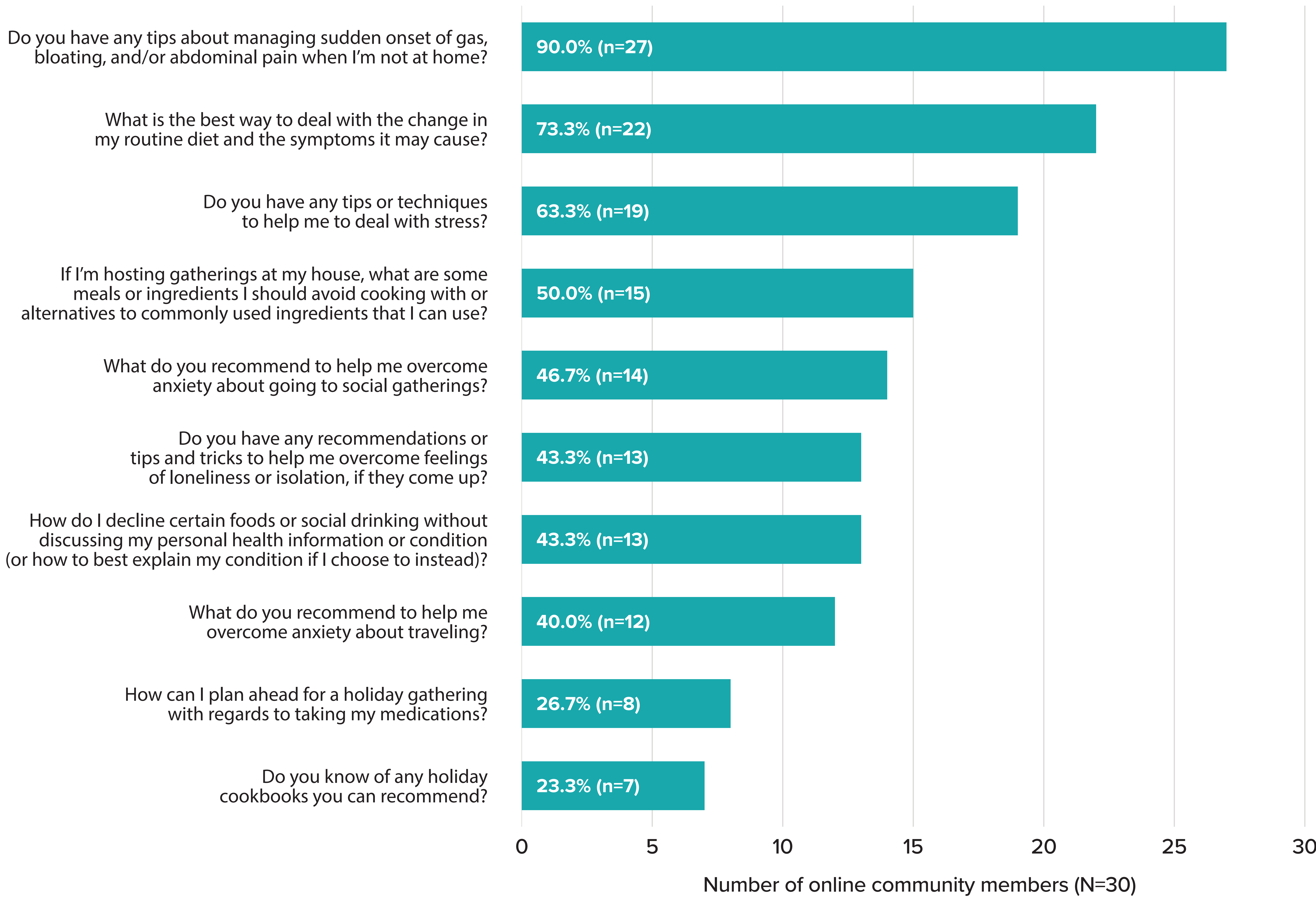
-  The online community, administered by HealthUnlocked and moderated by Mission: Cure, includes patients, care partners, and advocates
-  In addition to regular community activity, research events such as rapid polls, custom surveys, and expert-led events are conducted to collect real-world evidence
-  An online community research event was conducted to determine the most important lifestyle issues that people living with CP face during the holiday season
-  Online community members selected lifestyle questions from a list of 10 presented through a survey; the top 5 questions were answered by a gastroenterologist

## RESULTS

### Population

- Of the 30 responders in this survey:
  - 22 (73%) were diagnosed with CP
  - 12 (40%) were diagnosed with EPI
  - 5 (17%) were diagnosed with recurrent acute pancreatitis
  - 2 (7%) had suspected but unconfirmed CP
- Most respondents wanted to know more about symptom management outside the home, changes in diet, and stress (**Figure 1**)

**Figure 1. Healthcare Survey Questions for the Gastroenterologist**



## CONCLUSIONS



Results from this ongoing research event identified the importance of mental health, QoL, and symptom control challenges/concerns that patients with CP and/or EPI have on a day-to-day basis

The online community is identifying real-world evidence challenges that patients face, which may lead to improvements in quality of care and patient satisfaction



### References

1. Diéguez-Castillo C, et al. *Medicina (Kaunas)*. 2020;56(10):523.
2. Perbtani Y, Forsmark CE. *F1000Res*. 2019;8:1991.

### Acknowledgments

This study was sponsored by Aimmune Therapeutics, a Nestlé Health Science company. Writing and editorial assistance was provided by Stevin Joseph, PharmD, and Cheryl Casterline, MA (Peloton Advantage, LLC, an OPEN Health Company, Parsippany, NJ, USA), and funded by the study sponsor.

### Poster PDF

Copies of this poster obtained through QR Code are for personal use only.

