

Patient insight Gastroparesis

JAMES LIND INSTITUTE
NOVEMBER 2019 REPORT

Uncovering the symptoms and knowledge of gastroparesis among adults with diabetes. Revealing astonishing results about non-diagnosis and ignorance.



Introduction

James Lind Institute has been made aware of the disease gastroparesis as a condition with debilitating symptoms that negatively impact the daily living for people suffering from it.

Few satisfactory treatments exist, so we set out to investigate this disease by asking our community members about their knowledge of and symptoms of the disease.

Existing literature describes many interesting aspects of the disease, of which we have chosen to highlight the following:

- Long-standing diabetes is the most common known cause of gastroparesis
- Classic symptoms are nausea, stomach pain, vomiting, bloating and early satiety
- Most patients report these symptoms as being severe or very severe
- Most patients expect their health to get worse over time
- Most patients are not satisfied with the treatments available.



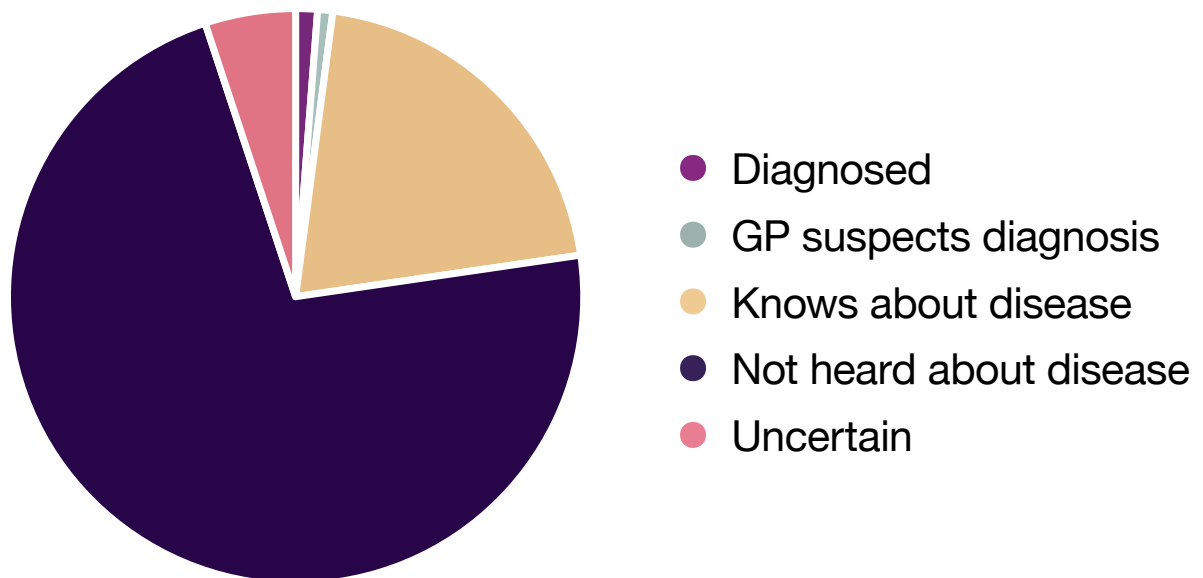
**1.045
answers
from our
community
members**

**Let us present the findings based on
1.045 answers from our community
members with diabetes.**

Gastroparesis is a rare diagnosis and an unknown disease among diabetics

Among diabetics in the age group of 30-70 years only 1.2% have the diagnosis of gastroparesis. Another 0.8% report that their GP suspects that they have the disease. In total 2%.

Furthermore only 20% of the patients have heard of gastroparesis.



Patient is diagnosed with gastroparesis	0,8%
GP suspects patient has gastroparesis	1,2%
Patient has heard of gastroparesis	21%
Patient has NOT heard of gastroparesis	72%



Birgit Hauggaard
Study Nurse

Living with chronic illness such as gastroparesis can sometimes feel like an insurmountable challenge. It can be demoralizing, scary, isolating, and frustrating.

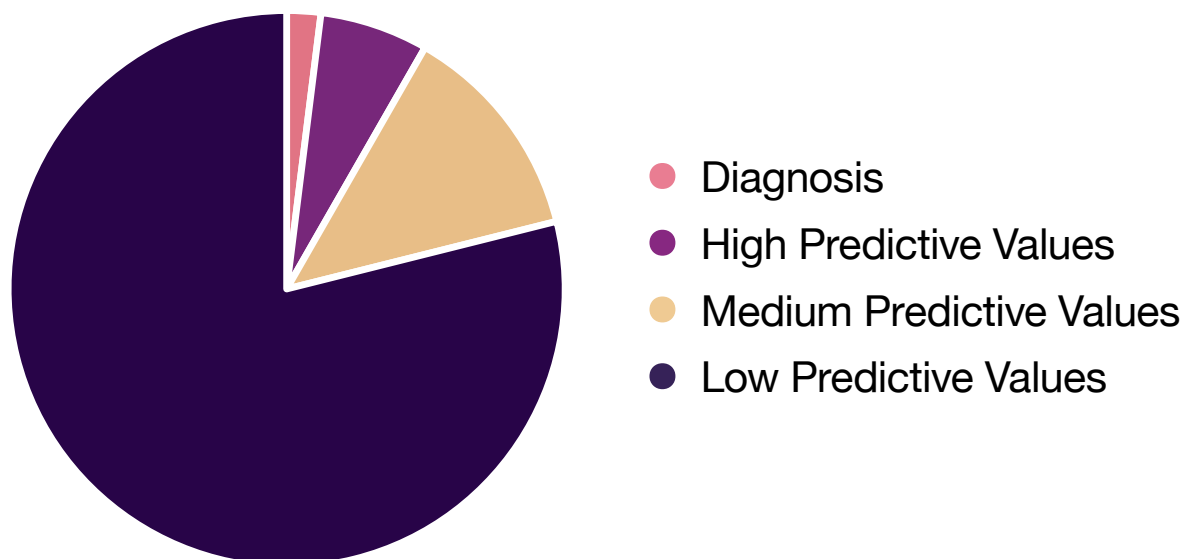
But living with an undiagnosed illness can be even worse. Based on data from the survey behind this report, it is fair to assume that people in high numbers live with severe symptoms of gastroparesis totally unexplained.

As a study nurse, I can easily imagine the terror and anguish these people face every day. A patient with these symptoms will know that something is indeed wrong with her body, but if her GP or specialist provides no answer, she continues to live in ignorance.

Many suffer from severe symptoms but are not informed and not diagnosed

6% of diabetics age 30-70 years experiences severe symptoms of gastroparesis, but only a fraction are diagnosed. As a consequence many patients are living with painful and bothersome symptoms without receiving any treatment.

According to existing literature on gastroparesis early diagnosis provides fairly good treatment.

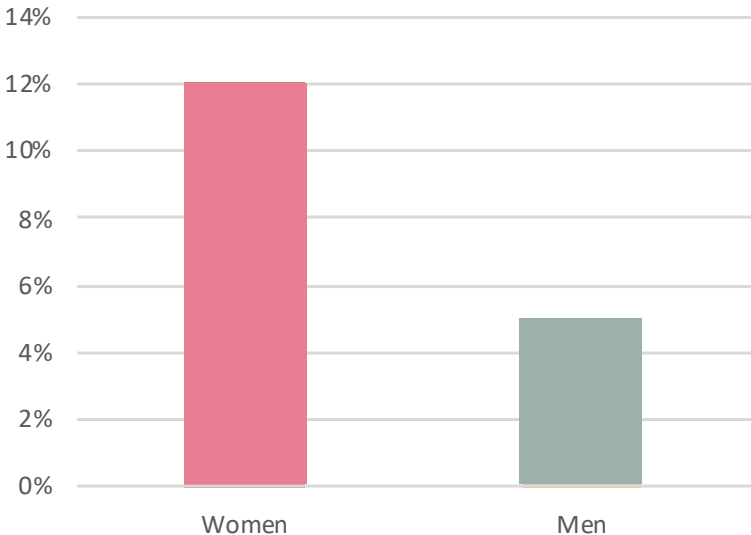


	Predictive Values		
Diagnosis	High	Medium	Low
2%	6%	13%	79%

Twice as many women as men have gastroparesis

Although few have the diagnosis, the well-known gender difference is confirmed by our members with diabetes. The pattern of twice as many women is clearly repeated in the High Predictive Value Group with severe symptoms.

This group consists of 69% women and 31% men.

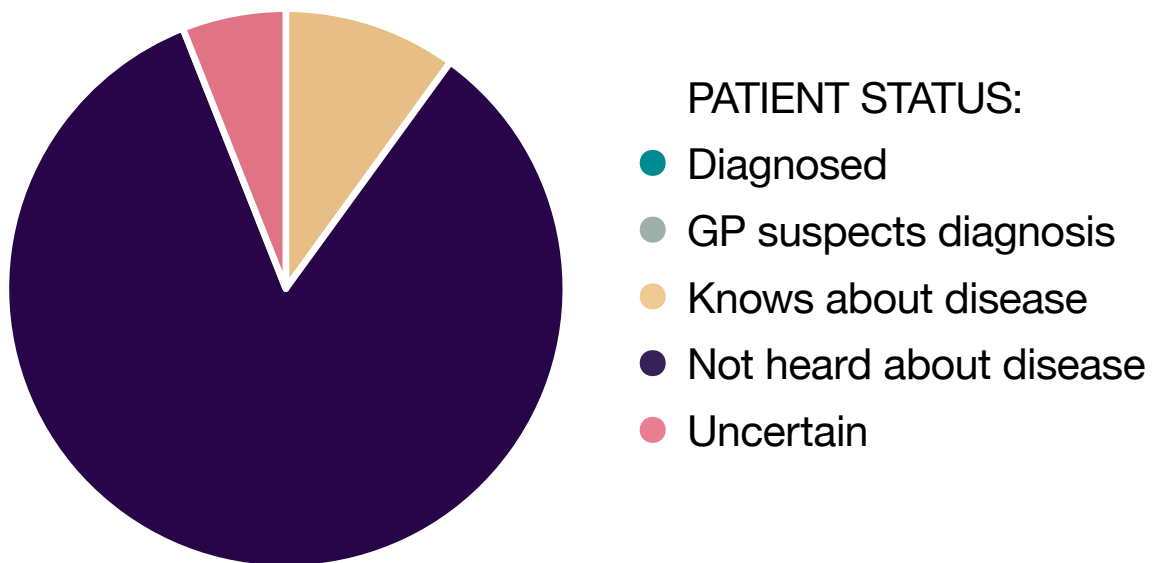


	Predictive Values			
	Diagnosis	High	Medium	Low
Women	3%	9%	14%	74%
Men	1%	4%	11%	83%

Adults with type 2 diabetics seem to be overlooked as potentially having gastroparesis

Despite the fact that severe symptoms of gastroparesis are as common among type 2 as among type 1, none with type 2 are being diagnosed, or even suspected by their GP of having gastroparesis.

Only very few people with type 2 have ever heard of gastroparesis.



Type 2

Patient is diagnosed with gastroparesis	0%
GP suspects patient has gastroparesis	0%
Patient has heard of gastroparesis	10%
Patient has NOT heard of gastroparesis	84%

Patients with severe symptoms often consult a physician without being diagnosed

Even though their symptoms are severe, patients consulting their GP or specialist are rarely diagnosed with gastroparesis.

This finding is most prominent among people with diabetes type 2, where 43% report having seen a specialist and none have been granted the gastroparesis diagnosis.

These findings point towards a need for communication about symptoms of gastroparesis. Such a campaign should be targeted to patients as well as to health professionals.

High Predictive Value Group

	No consultation	GP	Specialist	Both
Type 1	33%	7%	19%	42%
Type 2	20%	6%	43%	3%

1.063 diabetics age 30-70 years report their experience of any of these symptoms of gastroparesis.

This is what they tell:

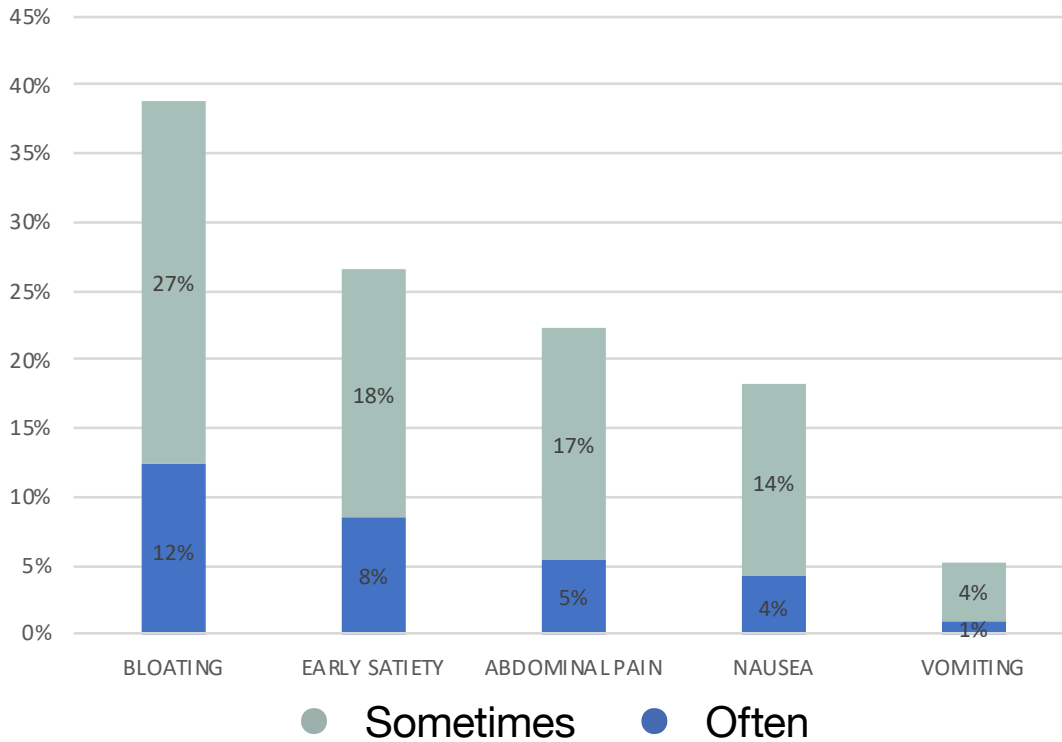
NAUSEA	Often	Sometimes	Rarely	Never
Type 1	6%	13%	29%	52%
Type 2	2%	15%	29%	54%

ABDOMINAL PAIN	Often	Sometimes	Rarely	Never
Type 1	5%	15%	29%	51%
Type 2	5%	19%	28%	48%

BLOATING	Often	Sometimes	Rarely	Never
Type 1	13%	23%	28%	36%
Type 2	12%	30%	23%	35%

VOMITING	Often	Sometimes	Rarely	Never
Type 1	0%	4%	21%	75%
Type 2	2%	5%	18%	76%

EARLY SATIETY	Often	Sometimes	Rarely	Never
Type 1	7%	17%	21%	56%
Type 2	10%	20%	20%	50%



The results align well with results from an IFFGD survey among 1,426 patients with the gastroparesis diagnosis. Here the diagnosed patients reported these symptoms:

- 51% Nausea**
- 46% Stomach pain**
- 30% Vomiting**
- 25% Bloating**
- 15% Stomach discomfort**

New Predictive Model

Based on the above James Lind Institute introduces a Predictive Model for the gastroparesis diagnosis. All symptoms are given the same weight. Answer “Often” is given value 3, “Sometimes” value 2, “Rarely” value 1 and “Never” value 0.

Predictive Model for Gastroparesis

Score value	3	2	1	0
	Often	Sometimes	Rarely	Never
Nausea				
Abdominal Pain				
Bloating				
Vomiting				
Early Satiety				

We have defined three categories:

High Predictive Value Group score 10-15 = severe symptoms

Medium Predictive Value Group score 7-9 = some symptoms

Low Predictive Value Group score 0-6 = no/few symptoms

Other questions and results

The data from our survey is more substantial than what is reported here. It also contains info on the following:

- Use of opioids and assessment of dependency
- Use of nausea relief medicines and assessment of dependency
- Treatment of diabetes

About the survey

James Lind Institute conducted the survey as an online questionnaire on 18.-23. September 2019.

We took out a random sample of 2.500 members of our community in Denmark to take part in the survey. The invited members are age 30-70 years and diagnosed with diabetes.

We received answers from 1.063 respondents. 541 have type 1 and 522 have type 2 diabetes. 577 are men and 485 are women.

The results are representative for our volunteer members, who have signed up with the purpose of being informed about research and clinical trials relevant to their disease.

**For further data analysis,
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About James Lind Institute

James Lind Institute is an international patient organization founded in 2011. It facilitates research focused patient communities in Europe, guiding patients in their clinical trial engagements.

Due to our many members and unique international character, James Lind Institute can take action on the issues confronting patient centricity in clinical trials, such as understandable communication, gentle protocol design, attentive enrollment, adequate feedback on research results, and more.

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