

# Gastroparesis in the Community Survey Summary Report

The Burdens, Concerns, and Quality of Life  
of Adults with Gastroparesis

An Online Study

Conducted by the  
International Foundation for Functional  
Gastrointestinal Disorders (IFFGD)

In collaboration with investigators from the  
Temple University School of Medicine



# Gastroparesis in the Community Survey

## Summary Report

### The Burdens, Concerns, and Quality of Life of Adults with Gastroparesis

The clinical descriptions of patients with gastroparesis – a chronic condition characterized by symptoms and slow gastric emptying – are mostly drawn from study of patients at academic medical centers, which are often taking care of the more severe type of patients. Descriptions of patients with gastroparesis in the community at large and the concerns that they have with their disorder have been lacking.

This survey sponsored by the International Foundation for Functional Gastrointestinal Disorders (IFFGD), and conducted by IFFGD in collaboration with clinical investigators from Temple University School of Medicine, was undertaken to more broadly describe patients in the community with gastroparesis and the clinical burden or impact on their lives that they experience from the patients' viewpoint.

Better understanding of the patient experience will help more effectively address their needs, helping to guide healthcare providers, treatment developers, and regulators.

Thank you to all the people with gastroparesis who participated in this research survey. Your voices will help improve clinical practice, medical research, and education about gastroparesis.

#### About the Survey

The confidential online survey instrument was administered by SurveyMonkey software. IFFGD posted the survey and opened it for the period beginning February 18, 2015 through May 31, 2015 to adults reporting a diagnosis of gastroparesis. Full detailed results are published in the peer-reviewed journal *Digestive Diseases and Sciences*\*, in order to more fully share the findings with the medical community.

All respondents in the survey report being diagnosed by a healthcare provider as having gastroparesis. A total of 1,423 adults aged 18 years and over completed the survey, including both the PGI-SYM and SF-36 sections that measure symptom severity and quality of life.

Milwaukee, WI  
February 2017



\* Yu D, Ramsey FV, Norton WF, Norton N, Schneck S, Gaetano T, Parkman HP. The burdens, concerns, and quality of life of patients with gastroparesis. *Dig Dis Sci*. 2017 Jan 21. doi: 10.1007/s10620-017-4456-7.

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## Highlights

- Gastroparesis leads to a variety of symptoms, and decreased quality of life
- Social function and general health are most negatively affected
- Respondents report nausea, vomiting, and stomach pain as most important symptoms to improve with treatment
- Onset of gastroparesis symptoms is gradual in 52% and sudden in 48% of respondents.
- On average the respondents report having gastroparesis symptoms for 9.3 years
- On average the diagnosis of gastroparesis was made 5.0 years after symptoms began
- Over half (52%) report their symptoms as being severe or very severe
- Bodily pain is severe or extremely severe in nearly half of respondents
- Nearly half the respondents expect their health to get worse over time
- A large number of respondents find out about treatments, not only from their physician, but also using the Internet, including social media
- Respondents report using multiple categories of drugs and other therapeutic approaches to treat their gastroparesis symptoms
- Most respondents (60%) are not satisfied with available treatments for gastroparesis
- Side effects from therapies are frequently reported
- Severe side effects occur most commonly with prokinetic agents, analgesic (pain) medications, and surgical procedures
- Complementary and Alternative Medicine (CAM) therapies have the least reported side effects and highest satisfaction rate
- Respondents most want specific treatments for their disorder

The results of this survey present a picture of chronic, debilitating symptoms, that negatively impact daily living, and for which there are few satisfactory treatments. More needs to be done to improve care and treatment for this patient population.

## Relationship with Providers

An accurate diagnosis from a physician is the starting point for effective treatment of gastroparesis. These respondents report their gastroparesis diagnosis was on average made 5.0 years after the symptoms began.

In 7 out of 10 respondents a gastroenterologist made the diagnosis.

Diagnosis was made by	% of respondents
Gastroenterologist (GI specialist)	72%
Primary care physician	10%
Surgeon	5%
Endocrinologist (diabetes specialist)	2%
Other	11%

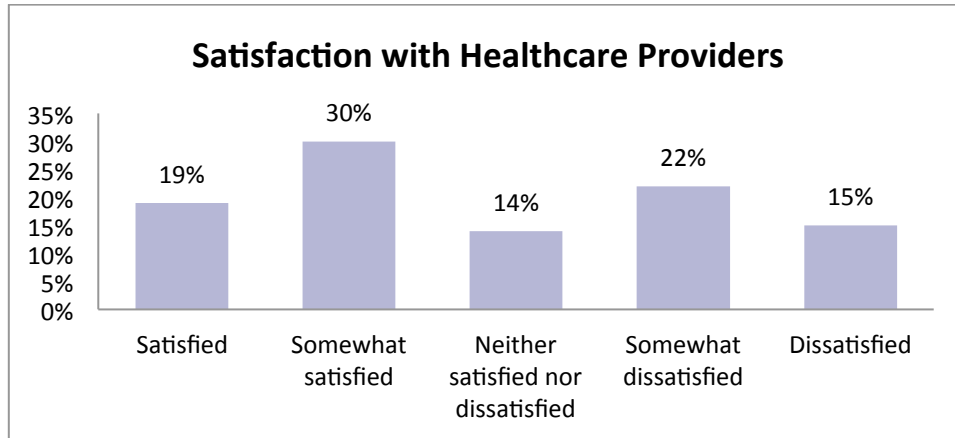
Respondents were asked what healthcare providers they saw for their gastroparesis during the prior 12 months.

Provider seen during prior 12 months	% of respondents
Gastroenterologist (GI specialist)	79%
Primary care physician	72%
Nurse practitioner	32%
Dietitian or nutritionist	32%
Physician assistant	26%

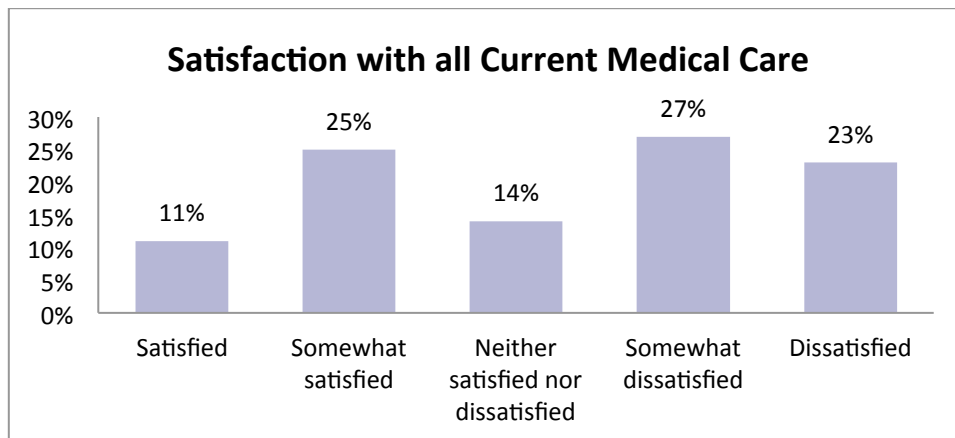
## Satisfaction with Healthcare Providers

Respondents were asked about their satisfaction with healthcare providers and with their current medical care.

When asked how satisfied they are with the medical care that they received for their gastroparesis in the last 12 months from their physicians and other healthcare providers, nearly half (49%) of respondents report being satisfied or somewhat satisfied, while over one-third (37%) report being dissatisfied or somewhat dissatisfied.



When asked, in general, how satisfied are they with all of the current medical care, including visits to providers, medications, and any other treatments that they currently receive for their gastroparesis, over one-third (36%) of respondents report being satisfied or somewhat satisfied and half (50%) report being dissatisfied or somewhat dissatisfied.



## Causes of Gastroparesis

The onset of gastroparesis symptoms was gradual in 53% and sudden in 47% of the respondents.

Respondents were asked, did the doctor who diagnosed you indicate a potential cause of your gastroparesis. Idiopathic gastroparesis (unknown cause) was most frequently suggested.

Potential Cause of Gastroparesis	% of respondents
Cause not known (idiopathic)	44%
Not told potential cause	15%
Diabetes	12%
Vagal nerve injury	5%
Virus	3%
Surgery*	3%
Autoimmune disorders	2%
Medication-induced**	1%

\*Of the 3% of respondents where surgery is the potential cause, gallbladder surgery was suspected in 37% followed by fundoplication surgery in 17%.

\*\*Of the 1% with medication-induced cause, narcotics are suspected in 41% and antirejection immunosuppressive medications in 17%.

## Coexisting Conditions

In addition to gastroparesis, most respondents also report having been diagnosed with other medical conditions. The most frequently reported is gastroesophageal reflux disease.

Other Medical Diagnoses Reported	% of respondents
Gastroesophageal reflux disease (GERD)	55%
Anxiety	42%
Depression	41%
Migraine	34%
Irritable bowel syndrome (IBS)	31%
Chronic constipation	26%
Fibromyalgia	19%
Diabetes	19%
Thyroid dysfunction	18%
Autoimmune disorder	13%
Chronic fatigue syndrome	13%
Neurologic disorders	9%

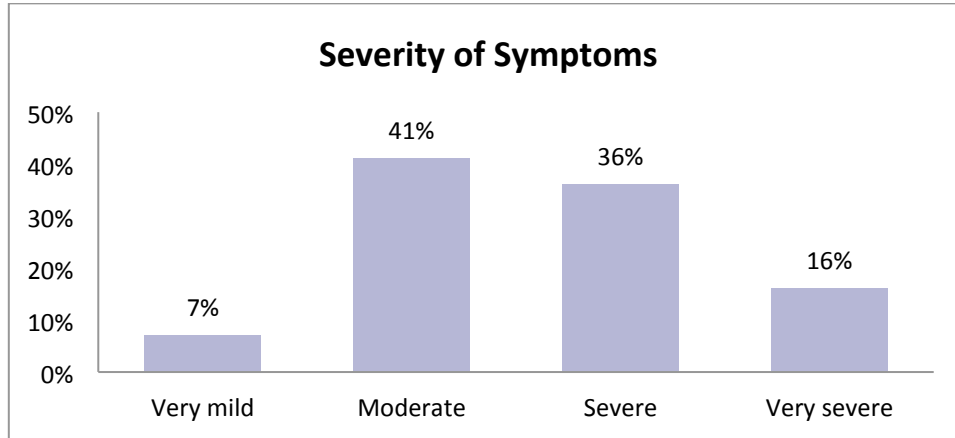
Five percent (5%) or less of respondents reported other diagnoses in each of several other conditions, including:

- Chronic intestinal pseudo-obstruction
- Cyclic vomiting syndrome
- Functional dyspepsia
- Eating disorders



## Symptoms and Severity

The respondents were asked to describe their severe and troubling symptoms of gastroparesis. Over half rate their gastroparesis as severe or very severe.



When gastroparesis symptoms are severe, the most troubling are nausea and stomach pain.

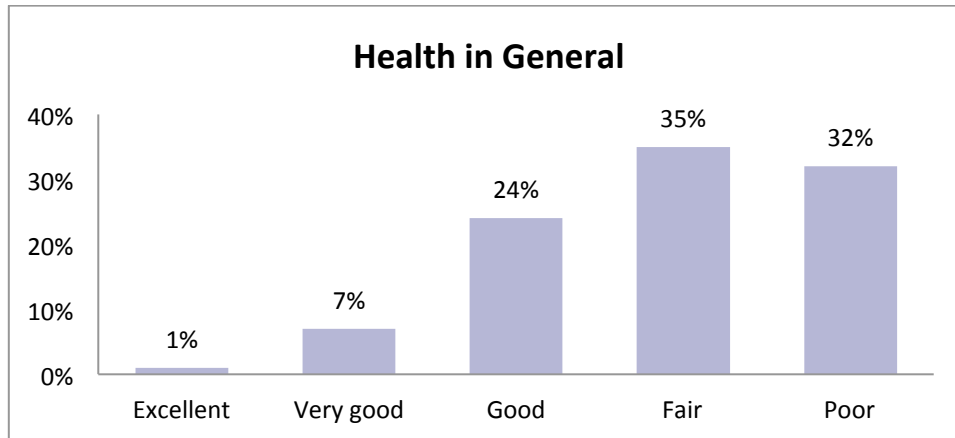
Most Troubling Symptoms	% of respondents
Nausea	51%
Stomach pain	46%
Vomiting	30%
Bloating	25%
Stomach discomfort	15%

Respondents were asked to rate severity of their symptoms during the prior 2 weeks on a numerical scale (PAGI-SYM) ranging from 0-none to 5-very severe.

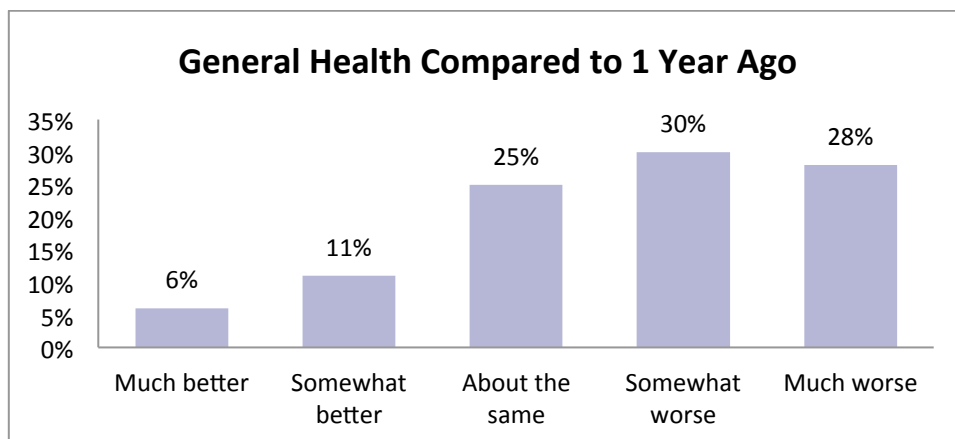
Symptoms Rated by Severity	Average Rating
Feeling excessively full after meal	3.9
Stomach fullness	3.8
Bloating	3.8
Unable to finish normal-size meal	3.7
Stomach/belly visibly larger	3.5
Upper abdominal (above the naval) discomfort	3.4
Nausea	3.4
Loss of appetite	3.3
Upper abdominal pain	3.2
Lower abdominal (below the naval) discomfort	2.9
Lower abdominal pain	2.5
Bitter, acid our sour taste in mouth	2.5
Heartburn	2.4
Regurgitation or reflux	2.3
Retching	1.9
Vomiting	1.8

## Daily Living and Quality of Life

When asked to rate their health in general, two-thirds (67%) rate it as fair or poor.



When rating their health in general now compared to one year ago, most (58%) report a worsening.



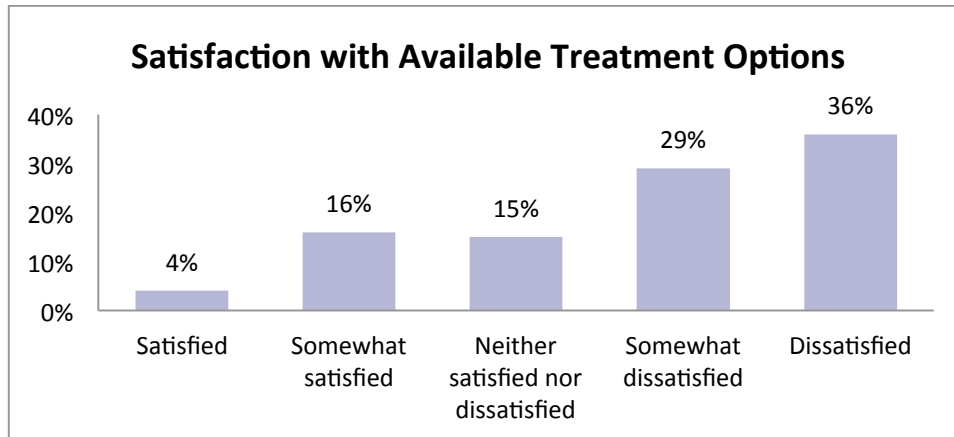
Over half of respondents (58%) say they expect their health to get worse over time.

Since their diagnosis of gastroparesis, 60% of respondents have lost weight, 18% have stayed the same weight, and 22% have increased weight.

Gastroparesis has a major effect on daily living, including social and work activities. Nearly one-third (30%) of respondents report they are not working because of the condition, and 15% report they are working limited hours because of their gastroparesis.

## Treatments for Gastroparesis

Respondents express dissatisfaction when asked, in general, how satisfied are they with available treatment options for their gastroparesis. One (1) out of 5 (20%) report being satisfied or somewhat satisfied, while 2 out of 3 (65%) report being dissatisfied or somewhat dissatisfied.



The respondents identified what symptoms are most important to improve with treatment.

Most Important to Improve with Treatment	% of respondents
Nausea	21%
Stomach pain	20%
Vomiting	11%

Respondents were asked what treatment measures for gastroparesis they had used in the past or were presently using, including:

- Dietary measures
- Complementary and alternative medicine (CAM) therapies
- Medications
- Surgical procedures

**Note:** In the survey questions, satisfaction reporting included: satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, or dissatisfied. Side effects reporting included: none, mild, moderate, or severe.

## ■ Treatments – Dietary Measures

**Dietary modifications** are made to try to control symptoms. Most current dietary advice is based on observations of what foods normally tend to promote or delay gastric emptying.

Respondents report having used one of these measures in the past or present:

Used %	Dietary Measures	Satisfied with Treatment	Side Effects Moderate or Severe
94%	Small frequent meals	32%	25%
90%	Low-fat foods	30%	18%
88%	Low-fiber diet	27%	25%
74%	Liquid nutritional products	30%	32%
54%	Avoiding carbonated drinks	52%	17%
54%	High-calorie liquids/blenderized meals	24%	30%
50%	Daily multivitamin	53%	17%
36%	Diabetes diet	27%	21%
17%	Feeding tube/enteral nutrition	29%	55%
16%	Central line/parenteral nutrition	37%	36%

N=1386

## ■ Treatments – Complementary and Alternative Medicine (CAM) Therapies

**CAM therapies** refer to approaches that are done in addition to conventional, or mainstream, medical treatments (complementary), or instead of conventional medical treatments (alternative).

Respondents report having used one of these therapies in the past or present:

Used %	CAM Therapies	Satisfied with Treatment	Side Effects Moderate or Severe
71%	Probiotics	45%	11%
61%	Ginger	42%	8%
58%	Dietary supplements	37%	15%
36%	Meditation	43%	3%
33%	Relaxation therapy	45%	2%
32%	Massage therapy	59%	6%
29%	Acupuncture	47%	8%
28%	Herbal therapy	40%	13%
19%	Homeopathy	36%	8%
17%	Guided imagery	43%	5%
15%	Biofeedback	20%	3%
11%	Chinese medicine	19%	15%
7%	Hypnotherapy	47%	3%

N=1322

## ■ Treatments – Medications

**Prokinetic, or promotility, agents** directly help the stomach empty more quickly and may improve symptoms such as nausea, vomiting, and bloating.

Respondents report having used one of these agents in the past or present:

Used %	Prokinetic Agents	Satisfied with Treatment	Side Effects Moderate or Severe
67%	Metoclopramide (Reglan, Metozolv)	23%	63%
46%	Erythromycin (Emycin)	25%	45%
44%	Domperidone (Motilium)	28%	34%

N=1363

**Antiemetic agents** are used to treat nausea and vomiting. These agents do not improve gastric emptying.

Respondents report having used one of these agents in the past or present:

Used %	Antiemetic Agent	Satisfied with Treatment	Side Effects Moderate or Severe
68%	Ondansetron (Zofran, Zuplenz)	43%	18%
66%	Diphenhydramine (Benadryl)	32%	22%
52%	Promethazine (Phenergan)	46%	28%
39%	Lorazepam (Ativan)	47%	23%
37%	Dimenhydrinate (Dramamine)	33%	20%
29%	Prochlorperazine (Compro, Compazine)	34%	36%

N=1352

*Treatments – Medications Continued*

**Analgesics** are medications taken to help control pain.

Respondents report having used one of these agents in the past or present:

Used %	Analgesic Medication	Satisfied with Treatment	Side Effects Moderate or Severe
48%	Oxycodone and paracetamol (Percocet)	53%	39%
47%	Tramadol (Ultram, Ultracet)	35%	30%
40%	Oxycodone (Oxycontin)	36%	39%
36%	Gabapentin (Neurontin)	41%	39%
34%	Hydromorphone (Dilaudid)	75%	32%
31%	Morphine (MSCotin)	63%	43%
31%	Amitriptyline (Elavil)	23%	44%
20%	Pregabalin (Lyrica)	39%	54%
13%	Nortriptyline (Pamelor)	46%	35%

N=1339

■ **Treatments – Surgical Procedures**

**Surgical procedures** for gastroparesis are generally infrequently done, for various purposes, when other treatments fail or in addition to other treatments.

Respondents report having used or had one of these procedures in the past or present:

Used %	Prokinetic Agents	Satisfied with Treatment	Side Effects Moderate or Severe
15%	Botox (botulinum toxin) injection	22%	15%
8%	Gastric electrical stimulation (GES) implanted	28%	37%
7%	Gastrojejunostomy	25%	48%
7%	Jejunostomy	34%	57%
5%	Gastrostomy for venting	51%	36%
3%	Pyloroplasty	29%	33%
2%	Completion gastrectomy	19%	52%

N=1328

## Sources of Information

Respondents were asked where they feel they receive good information regarding treatment options for their gastroparesis. Physicians (50%) are most frequently selected, and direct to consumer advertising (0%) is the least frequently selected.

### Sources of Good Information about Gastroparesis Treatment Options

% of respondents

- 50% Physicians
- 47% Internet
- 34% Facebook
- 29% Patient organization
- 27% Specialty sites
- 12% Web MD
- 10% Nurse practitioner
- 8% Government agency
- 8% Physician assistant
- 2% News media

## Profile of Participants

### Demographic Profiles of Survey Respondents

% of respondents

- 93% Under age 65 years
  - 30% age 18–34
  - 24% age 35–44
  - 22% age 45–54
  - 17% age 55–64
- 93% Female gender
- 7% Male gender
- 53% Employed
- 30% Not able to work because of gastroparesis
- 15% Working limited hours because of gastroparesis
- 84% Married or living as married
- 49% College degree
- 32% Some college
- 88% Living in USA

## Conclusions

Much remains to be understood about gastroparesis causes, treatment approaches, natural history, and burden of illness. The perspective of patients who struggle to bring symptoms under control while living daily with this disorder is a key part of raising awareness. This study addresses the need for healthcare providers in the general community to be better informed about their patients with gastroparesis and where to focus attention on treatment.

Half or more of the patients in this survey are 1) not satisfied with current treatments, 2) expect their health to get worse, and 3) want specific treatments for gastroparesis.

While patients want better treatments for all symptoms that characterize gastroparesis, they regard nausea, abdominal pain, and vomiting as the most troubling severe symptoms for treatment.

In this study, the physical health component of quality of life – more than the emotional or mental health component – is particularly decreased in patients with gastroparesis. Not only symptom severity, but also duration of symptoms over time, has negative effects. Many patients have other coexisting conditions, which add to the burden of their illness. Consideration of how best to improve quality of life for people with gastroparesis needs to be a part of all treatment plans.

Clearly gastroparesis is a condition that significantly impacts daily living and quality of life. Troublesome symptoms are many, and satisfactory treatments few.

There is a need for improved understanding about gastroparesis, among physicians and in the community. Research support needs to continue into prevention as well as treatments.

We hope this survey will help provide guidance about meeting the needs of all patients with gastroparesis.





International  
Foundation for  
Functional  
Gastrointestinal  
Disorders

## **Additional Information**

### **About IFFGD**

The International Foundation for Functional Gastrointestinal Disorders (IFFGD) is a nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal disorders. IFFGD has been working since 1991 with patients, families, physicians, practitioners, investigators, employers, regulators, and others to broaden understanding about gastrointestinal disorders and support research.

IFFGD  
PO Box 170864  
Milwaukee, WI 53217  
Phone: 414-964-1799  
Email: [iffgd@iffgd.org](mailto:iffgd@iffgd.org)  
[www.IFFGD.org](http://www.IFFGD.org)  
[www.aboutGastroparesis.org](http://www.aboutGastroparesis.org)