



INTRODUCTION

For individuals with celiac disease, accurate food labeling is essential for preventing immune-mediated disease activity and related health complications. In the United States, the Food and Drug Administration (FDA) regulates the use of the term “gluten-free” and defines the standard of “gluten-free” as <20 parts per million (ppm). Despite this regulatory framework, patients frequently report uncertainty regarding ingredient terminology, precautionary labeling, and the risk of gluten cross-contact during food manufacturing.

To ensure patient perspectives informed federal regulatory discussions, the Celiac Disease Foundation conducted a national consumer survey on experiences with gluten-free labeling. Findings were used to inform patient-centered comments submitted in response to the FDA’s Request for Information on gluten-free labeling and cross-contact risks (Docket No. FDA-2023-P-3942).

OBJECTIVES

This study evaluated:

1. Consumer confidence in current gluten-free labeling regulations
2. The role of labeling in purchasing decisions
3. Areas of labeling ambiguity identified by patients
4. Priorities for improving regulatory transparency and oversight

These consumer insights are real-world evidence that should direct regulatory actions to best protect and serve the consumer.

CONCLUSION

Survey findings directly informed recommendations to preserve the current gluten-free standard of <20 ppm. However, consumers noted the need to improve transparency regarding barley- and rye-derived ingredients, standardize precautionary labeling practices, strengthen disclosure of gluten cross-contact risks during manufacturing, and at minimum maintain current regulatory standards for gluten-free oats.

This project demonstrates how patient communities can generate real-world evidence that informs federal regulatory discussions. Future efforts will continue to leverage patient-generated data to inform regulatory decision-making and improve dietary safety for individuals requiring a gluten-free diet.

METHODS

Between **January 23 and February 20, 2026**, the consumer survey was distributed through the Foundation’s national patient network and partner organizations, including the Society for the Study of Celiac Disease, Gluten Intolerance Group, FARE (Food Allergy Research & Education), the National Health Council, Digestive Disease National Coalition, Autoimmune Association, and Bone Health and Osteoporosis Foundation.

Our survey received:

3,481 Responses



Public Comment on Labeling and Preventing Cross-Contact of Gluten for Packaged Foods; Request for Information
Docket No. FDA-2023-P-3942

Submitted by:

- Celiac Disease Foundation
- Society for the Study of Celiac Disease
- American Gastroenterological Association
- North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
- Gluten Intolerance Group
- FARE (Food Allergy Research & Education)
- Digestive Disease National Coalition
- Bone Health & Osteoporosis Foundation
- Center for Science in the Public Interest

Informed by real-world patient data and supported by leading health and professional organizations!

RESULTS

Results demonstrate **substantial consumer uncertainty** regarding current gluten-free labeling practices.

Confidence in Current Labeling

8.8% reported being extremely confident that foods labeled “gluten-free” are safe to consume.

2.1% believe current gluten-free labeling regulations adequately protect consumers with celiac disease.

Influence on Consumer Behavior

97.3% reported that gluten-free labeling influences purchasing decisions.

78% indicated that the gluten-free label is extremely important when selecting foods.

Reported Adverse Experiences

51.3% reported experiencing a reaction after consuming a product labeled gluten-free due to a suspected undisclosed gluten source.

Gluten-Free Oats Perceptions

80% reported consuming gluten-free labeled oats at least occasionally, suggesting broad acceptance of the inherent gluten-free nature of oats.

61.1% indicated that more transparency around oats would help them make safer food choices.



Food labels are a **critical safety tool** for people with celiac disease and others who must avoid gluten for medical reasons. This project shows how patient communities can generate real-world data about everyday challenges with food labeling and use that evidence to inform federal policy decisions.