

Use of Disease Symptoms Checklist in Self-Initiated Diagnoses of Celiac Disease and Non-Celiac Gluten Sensitivity

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In the U.S., clinician-initiated diagnosis (CID) of celiac disease (CD) and non-celiac gluten sensitivity (NCGS) is low. Little is known about the process when the diagnosis is self-initiated (SID). Websites offer a chance to better understand SID of CD and NCGS as 59% of U.S. adults access online health information. This study's aim was to understand diagnostic experiences of patients who use the web to prompt SID of CD or NCGS. CeliacCentral.org's health tool "Celiac Symptoms Checklist" provides patients the ability to identify CD/NCGS risk factors and share results with their clinician. Between March 2009 and May 2011, 54,891 individuals completed the Checklist. We conducted an online follow-up survey among Checklist participants on their health status since Checklist completion. The follow-up survey resulted in 2240 responses. Respondents were 90% female and 10% male. SID occurred in 38% of CD and 57.5% of NCGS cases. After SID, leading initiators were: Gastroenterologist (21.5%) and primary care (17.5%) for CD and 'Other' (13%), with chiropractor and naturopathic providers most commonly reported, and primary care (10%) for NCGS. In those diagnosed after completing the Checklist, SID occurred in 56% of CD and 65% of NCGS cases compared with CID in 31% of CD and 19% of NCGS cases. We demonstrate that CD and NCGS SID is common and an online tool used to survey CD/NCGS related symptoms and conditions may prove useful in prompting SID among U.S. patients. As online information commonly precipitates diagnosis, online resources must accurately reflect accepted diagnostic algorithms.

CD = celiac disease, NCGS = non-celiac gluten sensitivity, SID = self-initiated diagnosis, CID = clinician-initiated diagnosis

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Results of NFCA's "Celiac Symptoms Checklist," March 2009 - May 2011

The National Foundation for Celiac Awareness' online health tool "Celiac Symptoms Checklist"

Name, Email address and Zip code are recorded at the time of submission.
Available at www.DoiHaveCeliac.org

CELIAC DISEASE SYMPTOMS CHECKLIST

STEP 1: Complete this Celiac Disease Symptoms Checklist

While the symptoms of celiac vary, suffering from any of these symptoms — especially over time — may indicate that you should ask your doctor for a celiac blood test. Check all that apply to you, or your child.

***Be sure to click the continue button after you have submitted the form**

I (or my child) frequently experience:

<input type="checkbox"/> Bloating, gas and/or abdominal pain	<input type="checkbox"/> Heart to flush, bulky or loose stools
<input type="checkbox"/> Diarrhea or constipation	<input type="checkbox"/> Fatigue
<input type="checkbox"/> Itchy skin rash	<input type="checkbox"/> Tingling or numbness in hands and feet
<input type="checkbox"/> Discolored teeth or loss of enamel	<input type="checkbox"/> Canker sores
<input type="checkbox"/> Joint pain	<input type="checkbox"/> Irritability or behavior changes
<input type="checkbox"/> Significant unexplained weight loss	<input type="checkbox"/> Poor weight gain
<input type="checkbox"/> Delayed growth	<input type="checkbox"/> Missed menstrual periods
<input type="checkbox"/> Fractures or thin bones	

I (or my child) have been diagnosed with the following illnesses or conditions:

<input type="checkbox"/> Iron deficiency anemia	<input type="checkbox"/> Infertility
<input type="checkbox"/> Depression	<input type="checkbox"/> Osteoporosis or osteopenia
<input type="checkbox"/> Type 1 diabetes	<input type="checkbox"/> Thyroid disease
<input type="checkbox"/> Sjögren's disease	<input type="checkbox"/> Juvenile idiopathic arthritis
<input type="checkbox"/> Irritable bowel syndrome	<input type="checkbox"/> Intestinal cancer
<input type="checkbox"/> Peripheral neuropathy	<input type="checkbox"/> Down Syndrome
<input type="checkbox"/> Turner Syndrome	<input type="checkbox"/> Williams Syndrome
<input type="checkbox"/> Dermatitis herpetiformis	

☐ Check if you have an immediate family member who has been diagnosed with an autoimmune condition or celiac.

Frequently experiencing one or more of the symptoms listed, plus being diagnosed with any one of the diseases or conditions listed, may indicate that you have celiac.

CELIAC SYMPTOMS CHECKLIST

Step 2: Talk to your Doctor

This checklist is not definitive, but it can help facilitate a discussion with your doctor and highlight the need for further diagnosis.

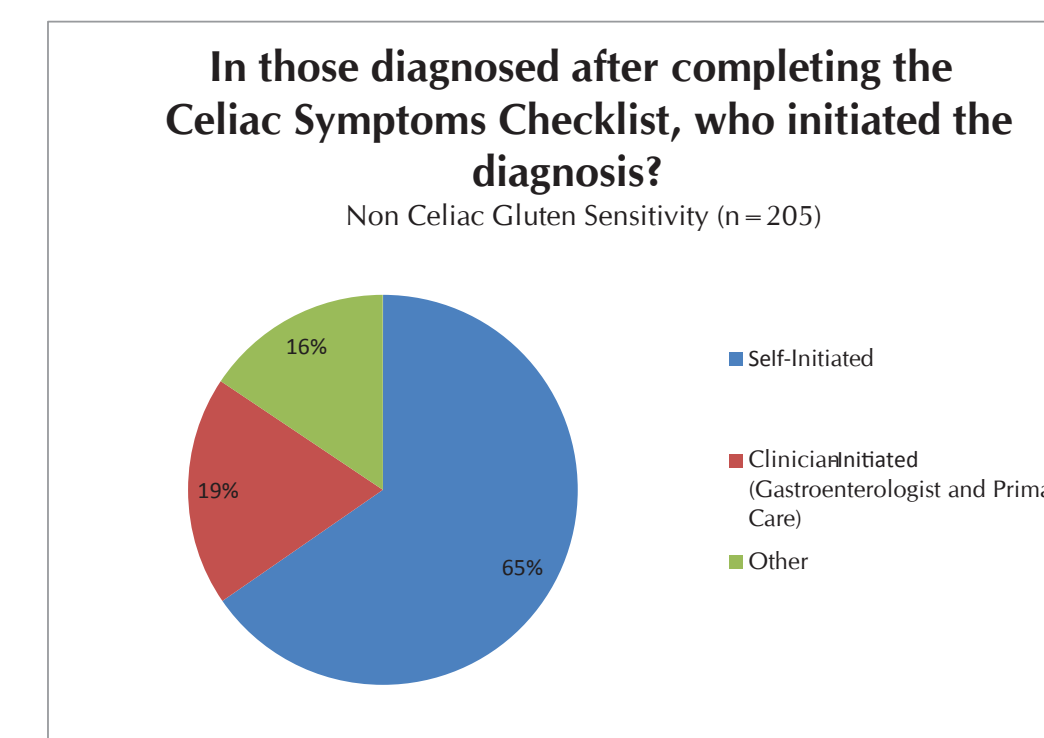
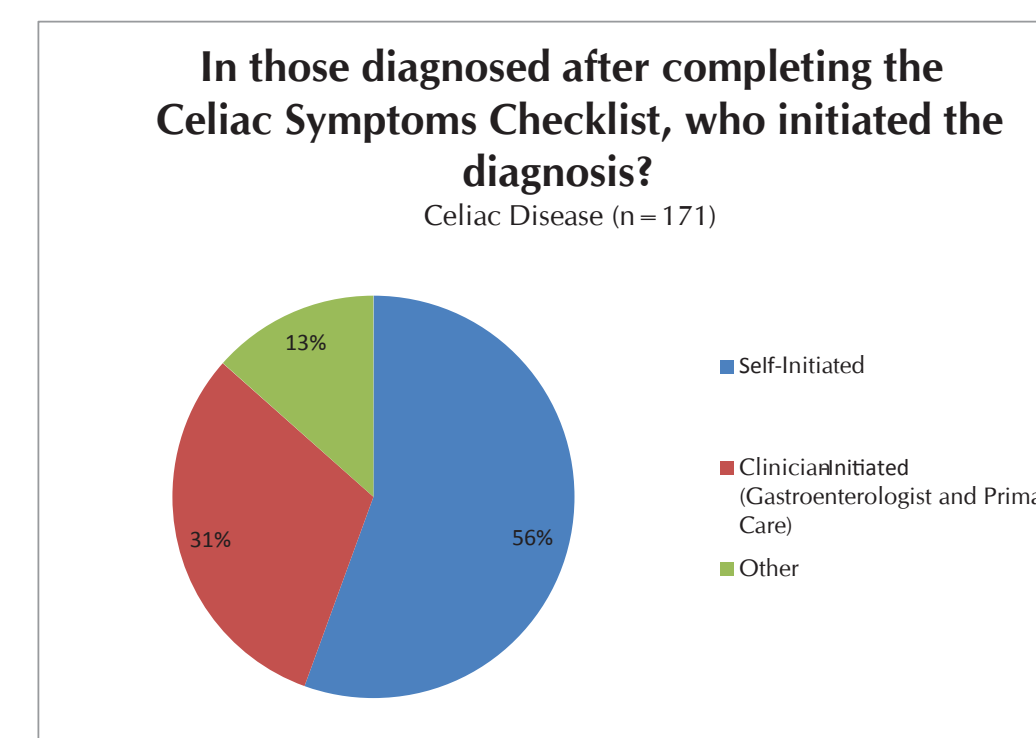
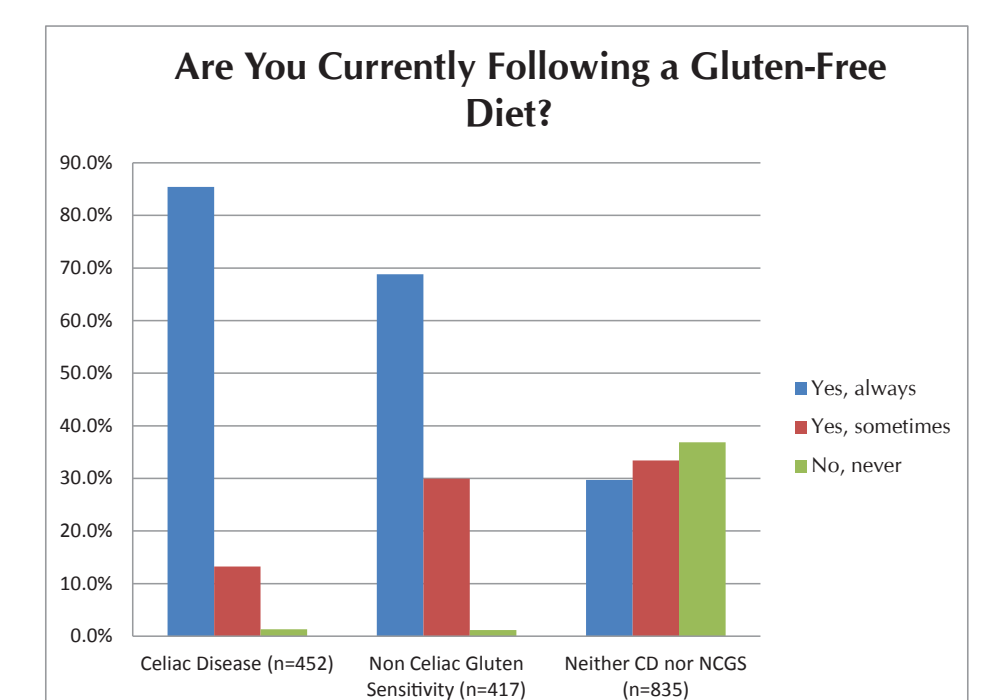
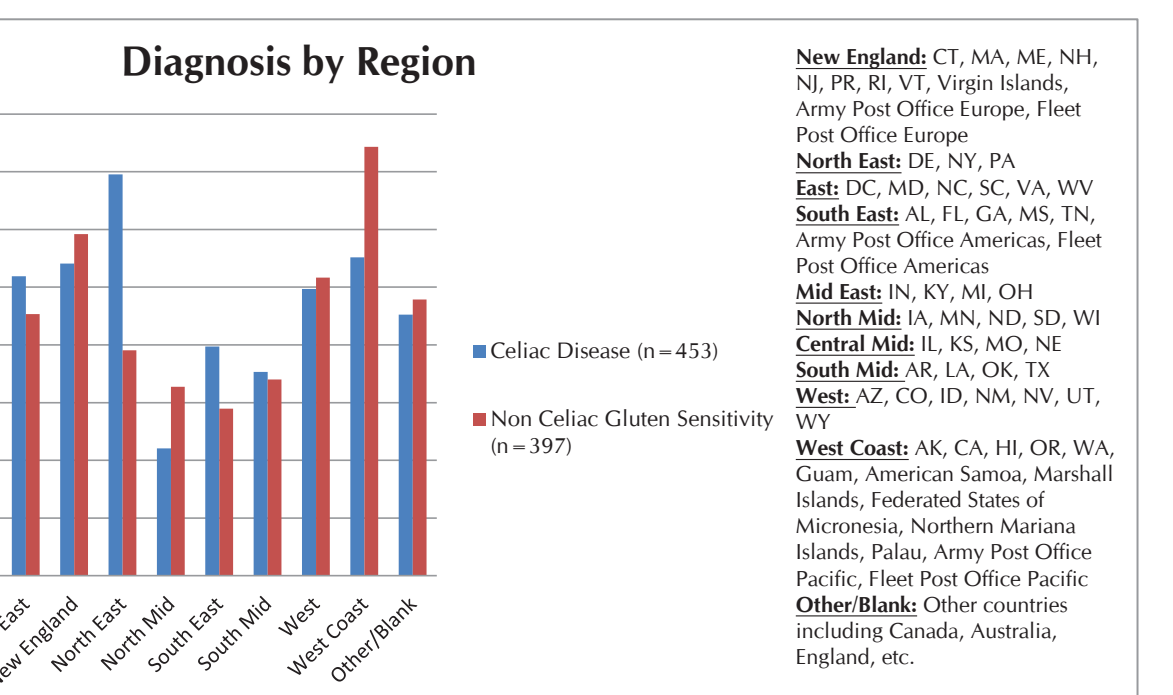
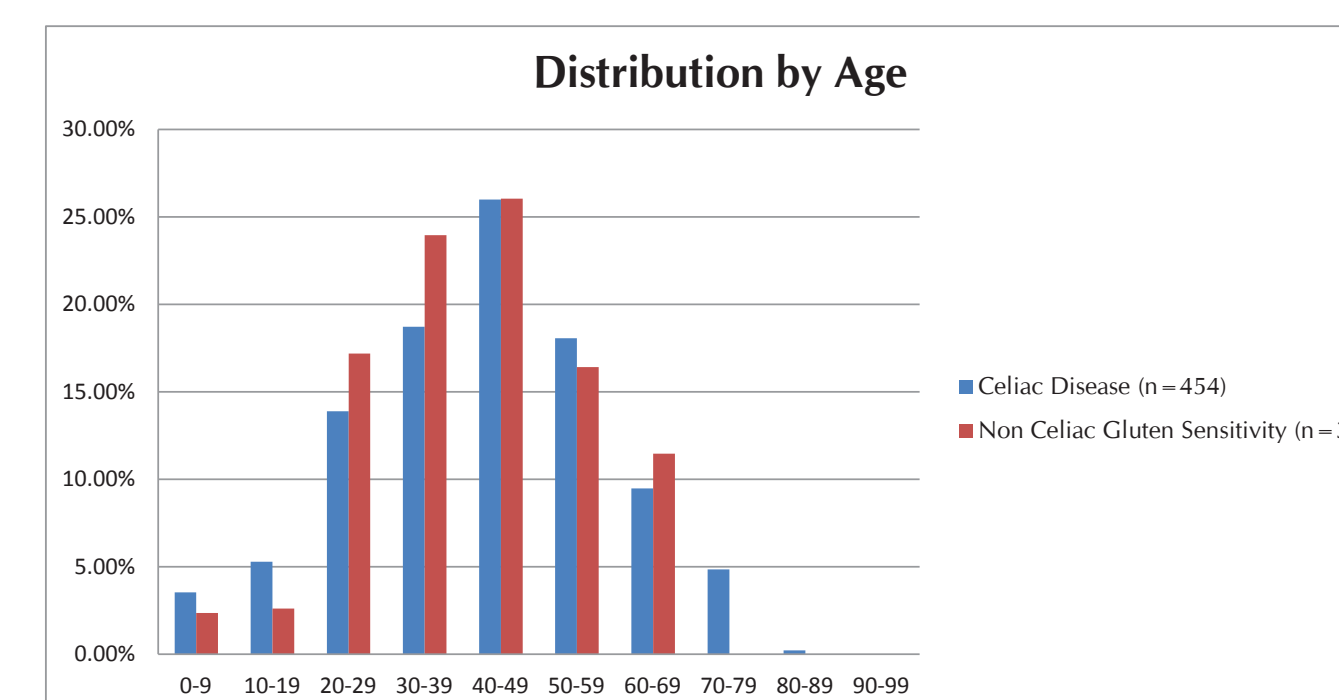
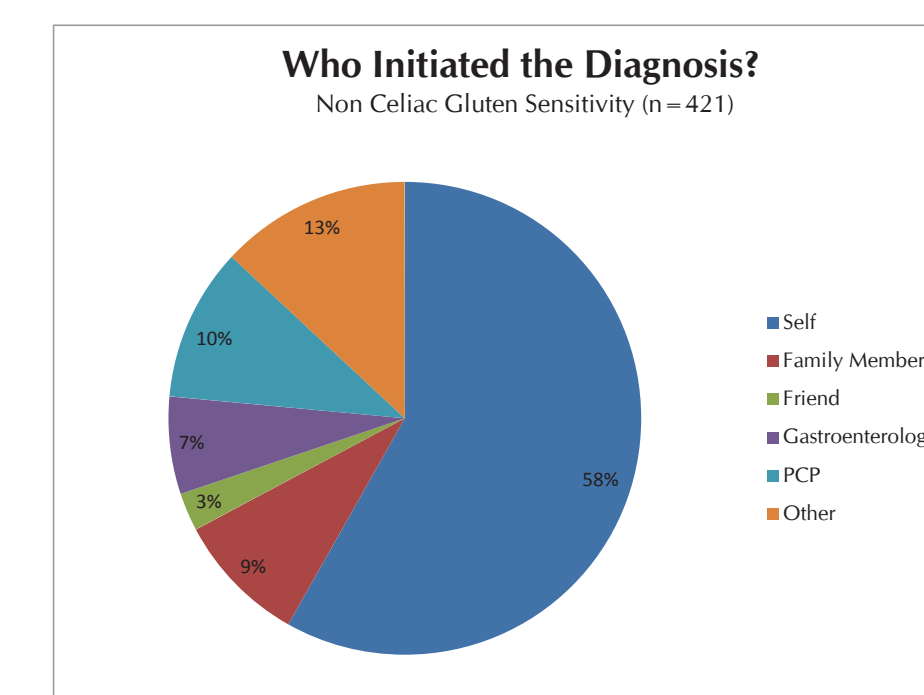
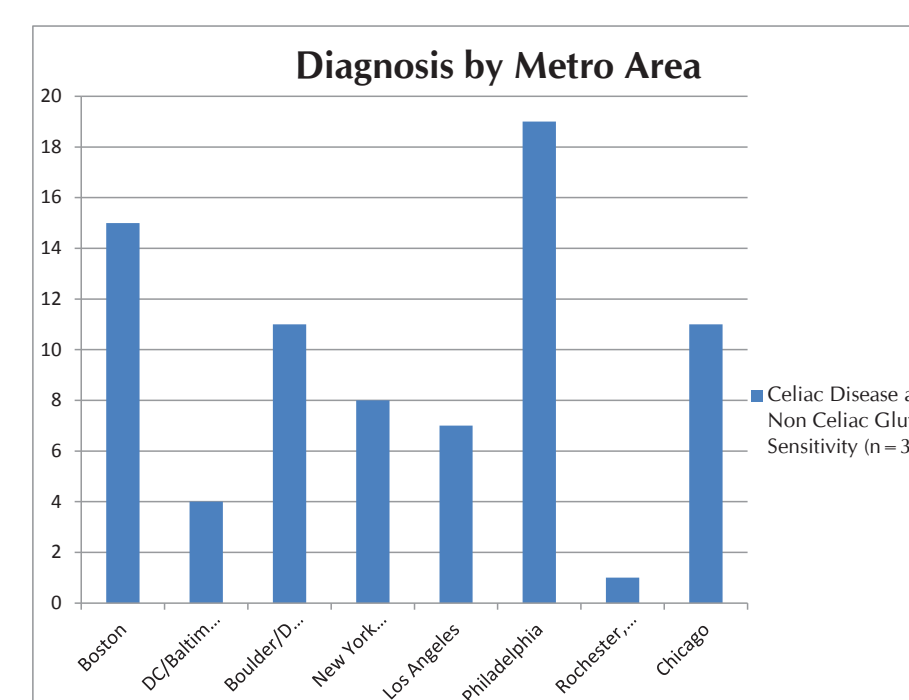
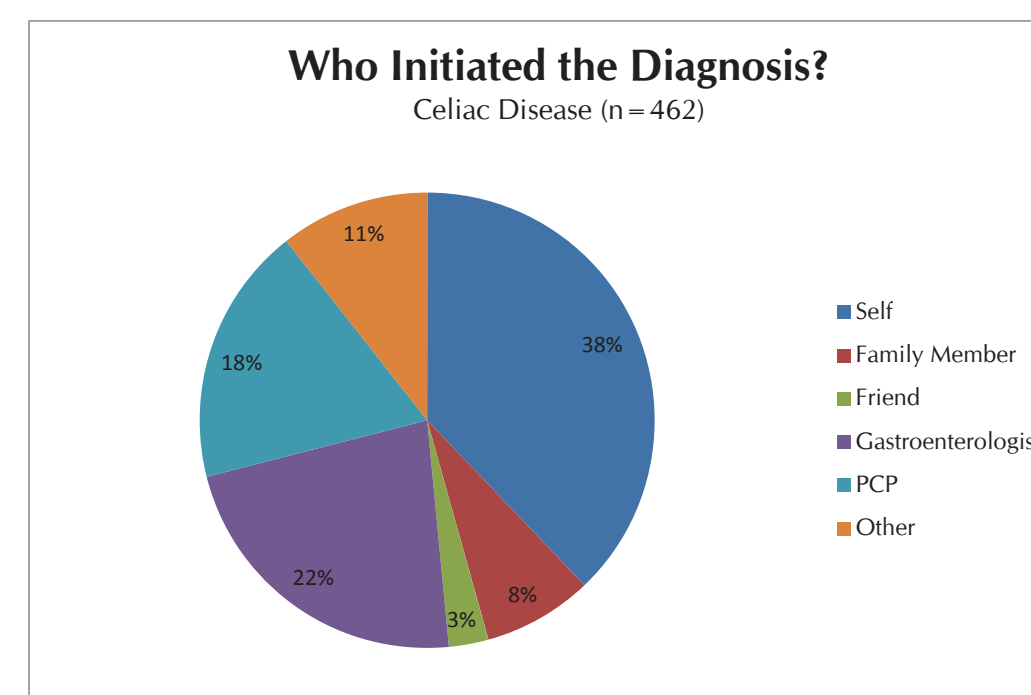
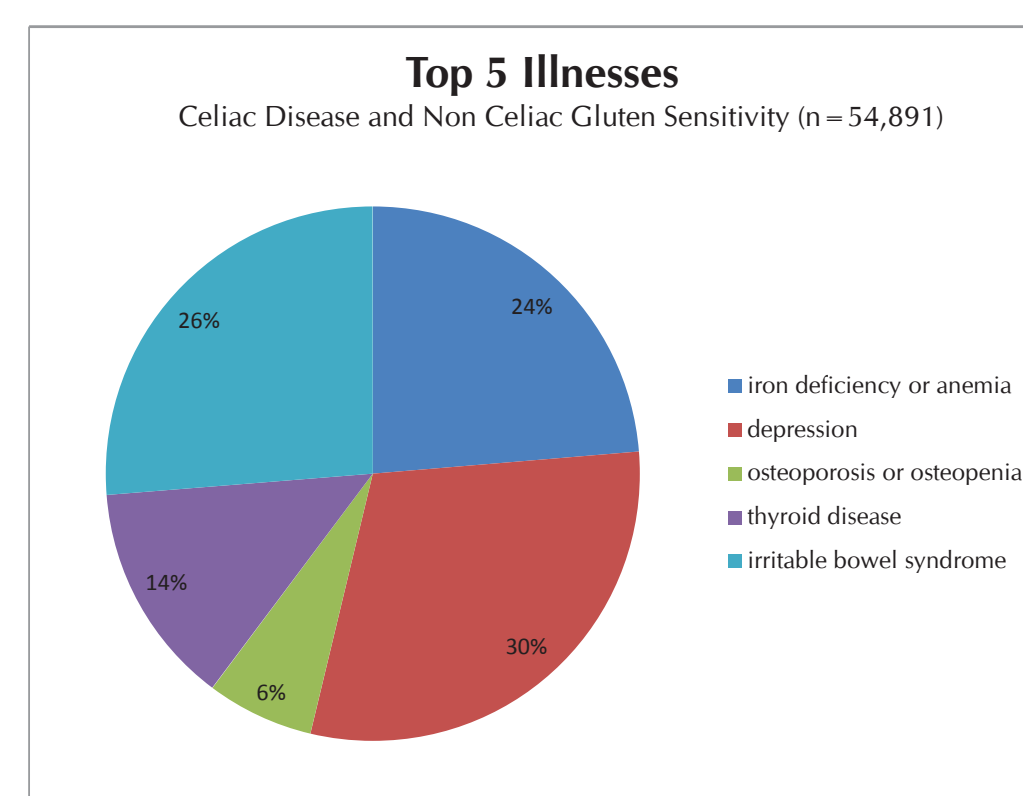
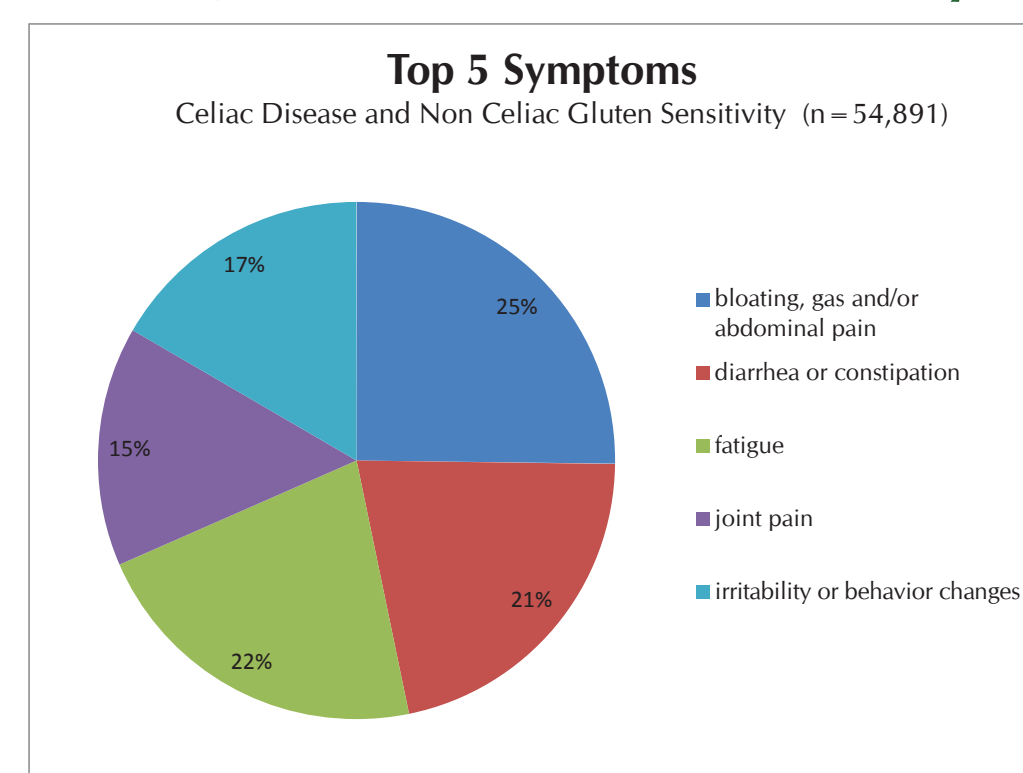
Currently, recommended tests include:

- Total IgA
- IgA-ITG
- IgA-EMA

• If IgA is deficient, it is recommended that the IgG/IgA-DGP also be ordered. At the discretion of the doctor, IgG-AGA can also be ordered.

**It is important to continue eating a normal, gluten-containing diet before being tested for celiac. If the blood tests and symptoms indicate celiac, a physician may suggest a biopsy of the lining of the small intestine to confirm the diagnosis.

If your doctor diagnoses you with celiac, please urge your family members to complete this checklist too.



Through empowerment, education and advocacy, the National Foundation for Celiac Awareness drives diagnoses and improves the quality of life for those affected by gluten-related disorders. We believe in a patient-centered healthcare model that is grounded in science, promotes collaboration and supports a comprehensive approach to health and wellness.

INNOVATIVE EDUCATION + FOOD + HEALTHCARE

CeliacCentral.org

the go-to place for information on celiac disease and the gluten-free diet

