

Introduction

Earlier this year we conducted a survey asking patients, their carers and healthcare professionals what unanswered questions they had about coeliac disease and/or other gluten related autoimmune conditions.

There were over **1000** respondents who in total submitted over **2500** research questions.

With the help of our [Steering Group](#) we have now grouped similar questions and summarised the groups to produce a shorter list of 43 research priorities.

We now need your help to find the top ten.

What we are asking you to do?

We need you to rank ten questions that matter to you the most from our list of 43 questions.

A pen and paper may be helpful to note key questions as you are reading through the long list.

Why are we doing this?

We want to give you a louder voice in research. People living with coeliac disease and/or another gluten related autoimmune condition, those caring for people with coeliac disease and healthcare professionals working in the field know the issues that affect them the most. We want to ensure that research addresses these issues and will potentially have the greatest impact.

Keeping your information secure

This is an anonymous survey but we will ask for a little information about you. This is so we can understand who is responding and ensure we're reaching as broad a range of people as possible. We won't be able to identify you in any of the survey results. We will keep the information you give us secure.

About you

Firstly, we need to know who is responding to our survey

*** 1. Please select from the list below which option *BEST* describes you. If more than one option applies to you, please select the capacity in which you choose to answer this survey:**

- A person living with coeliac disease and/or other gluten related autoimmune condition (eg dermatitis herpetiformis, gluten ataxia)
- A carer of a person living with coeliac disease and/or other gluten related autoimmune condition (eg dermatitis herpetiformis, gluten ataxia)
- A healthcare professional

*** 2. Which type of healthcare professional are you?**

- Dietitian
- Paediatric Dietitian
- Gastroenterologist
- Paediatric Gastroenterologist
- Neurologist
- GP
- Nurse
- Pharmacist
- Other

Please specify

Ranking your top ten

Of the 43 research questions below, we need you to pick out the ten that matter to you the most.

- * **3. Please select the ten questions where you think more research is needed and rank them from 1 to 10 with one being the highest priority and ten the least. Please leave all other questions blank. The list is fairly long so please make sure you read through to the end and a pen and paper may be useful to note key questions as you go along.**

Ranking of my top 10

What are the **triggers** (eg environmental, lifestyle, dietary, additional genetics) involved in the development of coeliac disease in people who are genetically predisposed to the condition ie HLA-DQ positive?

How can coeliac disease and associated complications be **prevented** in genetically vulnerable individuals (eg using drugs, vaccinations or modification of diet)?

What are the risk factors or underlying **triggers that determine when someone will develop coeliac disease** and/or **predict how severe** disease-associated symptoms and complications will be?

How does **ethnicity** affect the risk of developing coeliac disease?

How have **changes in the strains, production and processing of wheat** (eg genetic modification and use of pesticides) over the last 30 years contributed to the increase of coeliac disease?

How does **gut bacteria and/or antibiotics** play a role in the development of coeliac disease?

Could **probiotics** have a role in preventing or treating coeliac disease?

Is a **gluten free diet nutritionally adequate** and are there any consequences of being on a gluten free diet long-term, including those with other associated conditions eg Type 1 diabetes?

How can we improve the **nutritional status** of people with coeliac disease including a review of the **benefits / risks of supplementation**?

How can we better understand the causes of **refractory coeliac disease Types I and II** and use this understanding to develop and improve diagnosis and treatment?

Can **gluten free food products** be developed to have more similar nutritional properties to equivalent gluten containing products?

What are the best ways to **educate people working in the catering/hospitality industry** about the gluten free diet to improve safety for people with coeliac disease when eating out?

How can the accuracy of '**may contain**' **labelling** be improved?

Does going on a gluten free diet increase the **severity of symptoms experienced on subsequent exposure** to even small amounts of gluten, and if so what is the process?

What are the best methods to assess **individual levels of tolerance to gluten** in people with coeliac disease and / or other gluten related autoimmune conditions and how might this affect the ability to stick to the diet and health outcomes?

How can coeliac disease be **cured** so that consideration for a gluten free diet is no longer necessary?

Can a treatment be developed so people with coeliac disease and/ or other gluten related autoimmune conditions can **eat an increased level of gluten** eg on a special occasion OR to minimise the effects of **accidentally eating gluten**?

What is the **best means of follow up management** of people with coeliac disease and/or other gluten related autoimmune diseases, including help with sticking to the gluten free diet and prevention of long term health complications? (taking into consideration things like other conditions, age, education, socioeconomic status, mental health, no symptoms)

What is the best way to **educate people with coeliac disease and/or other gluten related autoimmune diseases** about their condition? (taking into consideration other conditions, age, education, socioeconomic status)

How long from diagnosis will it take for symptoms to disappear and the gut to heal and how might this vary depending on age, severity of damage, duration/type of symptoms vs no symptoms?

How long will it take and what are the key factors to **recover after accidentally eating gluten** and how might this vary from one individual to another?

How will **removal of access to gluten free food on prescription affect management and health outcomes** of people with coeliac disease?

Can a **self monitoring test** be developed for people with coeliac disease (and/or another gluten related autoimmune condition) to check they are sticking to a gluten free diet or are being exposed to gluten?

How can **healthcare professionals** be best supported to accurately diagnose and manage coeliac disease and other gluten related autoimmune conditions to achieve earlier diagnosis and improve patient care?

What are the best strategies to **increase awareness** and improve recognition of coeliac disease among the **general public** to achieve an **earlier diagnosis**?

Can a **portable user friendly device** be developed to test food and drink and identify if it is gluten free?

What is the **best support**, especially for vulnerable groups eg children, lower socioeconomic groups, people with learning disabilities, minority ethnic groups, that would help to improve **copng strategies and quality of life** when living with coeliac disease and or other gluten related autoimmune conditions?

What types of **mental health issues** may be seen in people with coeliac disease both before and after diagnosis, how common are such problems, what are the potential reasons and indications for treatment?

Can a **test** be developed to identify those people who **react to gluten free oats**?

How can we better understand the associations between coeliac disease and **other conditions** eg Type 1 diabetes, autoimmune thyroid disease, and what factors influence the risk of developing such conditions?

What are the benefits and harms of having a **national population screening programme** for coeliac disease rather than focusing on a risk based approach and what is the best age for screening in this way?

Do **viral and bacterial infections** influence onset of coeliac disease and are people with coeliac disease, either diagnosed or undiagnosed, more prone to these infections?

What are the indications and risks of 'over the counter' rapid **kits for self-testing** for coeliac disease?

Can **tests** be developed for **distinguishing different forms of gluten related conditions**?



What is the **spectrum of neurological forms of coeliac disease** and how does neurological dysfunction develop? How are they **best diagnosed and managed**?



What is the process underpinning the association between coeliac disease and **low fertility** and does exclusion of gluten wholly restore fertility?



Are there different mechanisms (apart from vitamin D deficiency and chronic malabsorption of calcium) affecting the development of **osteoporosis** in coeliac disease and if so what are they and how can our understanding help us to identify and improve outcomes for those at risk?



Why do some people develop **Dermatitis Herpetiformis (DH)**, are there other skin conditions associated with coeliac disease that respond to exclusion of gluten in the diet and how can DH and any other associated skin conditions be better recognised, diagnosed and managed?



What is the prevalence and cause of **fatigue** in coeliac disease and how can this information be used to reduce its impact?



Are there **less invasive tests** (apart from gastroscopy and duodenal biopsy) for recognising coeliac disease and is it possible to accurately test for coeliac disease once **gluten has been excluded from the diet**?



How much does it **cost to produce gluten free substitute foods** and can it be reduced?



How can a greater understanding of the **genetics support the development of new treatments** for people with coeliac disease?



How can **knowledge and understanding across autoimmune / inflammatory diseases** be used to advance understanding of coeliac disease and gluten related autoimmune diseases to achieve the best health outcomes for patients?



About you

It would be helpful for our research to know a little more about you to help us understand the range of people responding to the survey. We won't use your data for any other purposes.

4. Are you...

- Male
- Female
- Prefer not to say
- Other (please specify)

5. What is your age?

- Under 16
- 16 - 25
- 26 - 30
- 31 - 40
- 41 - 50
- 51 - 60
- 61 - 74
- 75 and over
- Prefer not to say

6. Where do you live?

- South East England
- South West England including the Channel Islands
- Greater London
- East of England
- West Midlands
- East Midlands
- Yorkshire and the Humber
- North East England
- North West England including Isle of Man
- Wales
- Scotland including Scottish Islands
- Northern Ireland
- Other (please specify)

Thank you for your time, your participation in this survey is much appreciated.

What happens next:

We'll take the questions with the most votes forward to a final workshop on 1 February, 2018. At this workshop we will bring together people with coeliac disease and/or other gluten related immune conditions (eg gluten ataxia, dermatitis herpetiformis), those caring for people with coeliac disease and healthcare professionals to decide which questions should feature in the list of top ten research priorities.

After the workshop, the top ten research priorities will be formally announced at our annual Research Conference, 15 March, 2018. These questions will guide what research we will fund and we'll make sure other organisations that fund research know how important the priorities are.

Thanks again for your time. Please look out for the research priorities feature in our Summer 2018 Crossed Grain magazine, our [website](#) and social media channels.