

Coeliac Disease Priority Setting Partnership – pre-workshop exercise

Individual ranking of questions for the workshop on 1 February 2018

This is a list of 26 questions for coeliac disease research. They have come from a survey of individuals with coeliac disease and other gluten related immune conditions (eg dermatitis herpetiformis and gluten ataxia), family members/carers and health professionals. They have been checked against current evidence to ensure they have not already been comprehensively answered. Please spend some time **before** the workshop reviewing this list of questions. Rank them from 1–26, 1 being the most important in your opinion and 26 being the least important, for research to address. Make a note of any comments in the right hand column.

Please bring this completed form with you to the workshop.

Ref	Question	Your ranking (1-26)	Notes
A	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?		
B	How can coeliac disease and associated complications be prevented in genetically vulnerable individuals (eg using drugs, vaccinations or modification of diet)?		
C	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?		
D	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?		

E	How much does it cost to produce gluten free substitute foods and can it be reduced?		
F	How does gut bacteria and/or antibiotics play a role in the development of coeliac disease?		
G	What is the spectrum of neurological forms of coeliac disease and how does neurological dysfunction develop? How are they best diagnosed and managed ?		
H	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?		
I	How can we improve the nutritional status of people with coeliac disease including a review of the benefits / risks of supplementation ?		
J	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?		
K	Are there less invasive tests (apart from endoscopy 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 ?		
L	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?		
M	How can the accuracy of ' may contain ' labelling be improved?		
N	What is the prevalence and cause of fatigue in coeliac disease and how can this information be used to reduce its impact?		

O	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?		
P	How can coeliac disease be cured so that consideration for a gluten free diet is no longer necessary?		
Q	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?		
R	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)		
S	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?		
T	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?		
U	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?		
V	How will removal of access to gluten free food on prescription affect management and health outcomes of people with coeliac disease?		

W	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?		
X	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?		
Y	What are the best strategies to increase awareness and improve recognition of coeliac disease among the general public to achieve an earlier diagnosis ?		
Z	Can a portable user friendly device be developed to test food and drink and identify if it is gluten free?		