

Defining the optimum strategy for identifying adults and children with coeliac disease: systematic review and economic modelling

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Plain English summary

Optimum strategy to identify coeliac disease

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Plain English summary

What is the problem?

Around 1 in 100 people in the UK has coeliac disease. It develops when the immune system attacks the lining of the gut after eating gluten. It is thought that only one in three people with coeliac disease is currently diagnosed. Without treatment, people with coeliac disease are at an increased risk of anaemia, osteoporosis and cancer. Treatment is a lifelong gluten-free diet.

Diagnosing coeliac disease is difficult. Some people have minimal or non-specific symptoms, such as pain, indigestion or bloating, so knowing who to test is tricky.

What did we do?

We wanted to establish who should be tested for coeliac disease, what tests should be used and whether or not invasive testing (a gut biopsy) is necessary for everyone. We looked at existing studies and data from general practices, and conducted an online survey, and brought everything together in an economic (cost) analysis.

What did we find?

Using individual symptoms is not helpful to identify people who may have coeliac disease. People with coeliac disease are more likely to have a combination of symptoms. People with anaemia, type 1 diabetes, osteoporosis, thyroid disorders, immunoglobulin A deficiency, Down syndrome, Turner syndrome or a family history of coeliac disease are more likely to have coeliac disease and should be offered tests.

Common blood tests for coeliac disease are very accurate, particularly when used in combination with genetic testing. Blood tests alone can be used for diagnosis for some people. Others will need a biopsy to confirm the diagnosis. Whether or not this is needed depends on their risk of coeliac disease: whether or not they have symptoms and whether or not they have a condition that puts them at higher risk. Shared decision-making is important for individuals considering an invasive test, depending on how certain they want to be about their diagnosis before starting a gluten-free diet.

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This report

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