Diagnosis of coeliac disease: NICE guidelines

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Background

- CD is thought to be present in ~1% of the UK population but only 10-15% of cases have been diagnosed.
- Some of the undiagnosed people have chronic problems such as lethargy, gastrointestinal symptoms or anaemia & they often undergo extensive investigation without a definite diagnosis.
- The Department of Health asked NICE to produce a short clinical guideline about how CD should be recognised and which people should be assessed for CD.
The guideline does not cover

- Management of CD
- Using endoscopic biopsy to diagnose CD
- Population-based screening for CD
- The accuracy & use of self-diagnosis kits
The guideline development group

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Prevalence of coeliac disease

Prevalence of CD W Europe & N America is between 0.8% and 1.9%.

Among first-degree relatives of people with CD, most studies report a prevalence of 4.5% - 12%.

There is limited evidence that the prevalence of CD is twice as high in females as in males.
Possible long-term consequences of undiagnosed coeliac disease

Undiagnosed maternal CD has a negative effect on intrauterine growth & birth weight & is associated with increased preterm birth & caesarean section rates.

Increased risk of fractures, non-Hodgkin’s & Hodgkin’s lymphoma & small bowel cancer, but overall rates of malignancy are low.

Growth failure, delayed puberty and dental problems (in children).
Serological testing

The IgA tissue transglutaminase & IgA endomysial antibody serological tests have high sensitivity & specificity.
Recommendations I

Offer serological testing to children & adults with any of the symptoms or signs associated with CD including:

- persistent or unexplained gastrointestinal symptoms inc chronic or intermittent diarrhoea, nausea, vomiting, abdominal pain, cramping, distension
- sudden or unexpected weight loss
- prolonged fatigue
- unexplained anaemia
- failure to thrive or faltering growth (children)
Recommendations II

Offer serological testing for CD to children & adults with any of the following:

- autoimmune thyroid disease
- dermatitis herpetiformis
- irritable bowel syndrome
- type 1 diabetes
- first-degree relatives with CD

Do not use serological testing for CD in infants before gluten has been introduced to the diet.
Recommendations III

Offer referral to a gastrointestinal specialist for intestinal biopsy to confirm or exclude CD to people with positive serological results from any tTGA or EMA test.

If serology tests are negative but CD is still clinically suspected, offer referral to a gastrointestinal specialist for further assessment.
Inform people that any testing for CD is accurate only if the person continues to follow a gluten-containing diet during the diagnostic process.

They should not start a gluten-free diet until diagnosis is confirmed by intestinal biopsy, even if a self-test or other serological test is positive.
Research questions I

What is the minimum gluten dietary content necessary for the optimal accuracy of serological tests & intestinal biopsy for the diagnosis of CD?

How many people with undiagnosed coeliac disease are misdiagnosed as having other conditions, what are the clinical & cost implications of this?
Research questions II

Should repeat serological testing for CD be performed, & if so, how often?

Does adherence to a gluten free diet improve diabetes-related outcomes in people with CD & type 1 diabetes?

Is the prevalence of CD higher in adults & children with autism than in the general population?
Thank you

Any questions?