



Cover Sheet and Consultation Responses on Screening for Coeliac Disease in Adults

Aim

1. To agree the UK National Screening Committee's (UK NSC) formal policy position on screening for coeliac disease in adults.

Background

2. This is a repeat review of screening for coeliac disease in adults, with the first review undertaken by Professor David Sanders in 2008 that recommended against screening. This was due to;
 - a. the lack of clear understanding of the natural history of individuals with coeliac disease
 - b. a lack of evidence on early recognition being beneficial,
 - c. the lack of evidence that patients detected by screening would adhere to a gluten free diet
 - d. financial limitations that had not been considered in the cost-effective models and
 - e. the lack of literature showing the acceptability of the test to histologically confirm the diagnosis of coeliac disease
3. The current review uses a selective criteria format focussing on areas of the 2008 review, above, that were previous unmet.

UK NSC review of screening

4. Dr Jackie Spiby, a Public Health Consultant, was asked to focus the review around those particular criteria and did not find a significant change in the evidence base to warrant changing our current policy
5. In particular, the review found;
 - a. the clinical course of undiagnosed coeliac (likely to be detected at screening) was still poorly understood
 - b. no evidence of health gain from treatment given to asymptomatic, screened populations
 - c. some evidence suggesting lower adherence to treatment than people with symptoms of coeliac

- d. No UK cost-effectiveness studies but evidence from a study of US primary care data that screening was not cost-effective (using NICE's upper threshold of £30,000 cost per QALY gained)
- e. Further research is needed to identify the best series of tests to confirm a case of coeliac disease.

Consultation and responses

- 6. The consultation was open for three months and closed on 20th January 2014.
- 7. Two responses were received from the consultation (with the complete responses in Annexe A).
- 8. One from Coeliac UK, who supported the need for enhanced education of GPs and physicians to identify coeliac disease. They also emphasised the need for high quality evidence from RCTs to inform future reviews of screening.
- 9. The second response was from Professor David Sanders, who undertook the 2008 review of Coeliac disease, was regarding terminology. This has subsequently been amended.

Recommendation

- 10. The UK NSC is asked to not to recommend screening for coeliac disease in adults.
- 11. The UK NSC is asked to agree that the policy should be reviewed in 3 years.

**Annexe A –
Consultation Responses**

**UK National Screening Committee
Screening for Coeliac Disease in Adults - an evidence review**

Consultation comments

1.

Organisation:	Coeliac UK		
Name:	Sarah Sleet	Email address:	XXXXXXXXXXXX
Please tick whether you are making this submission as an individual or on behalf of an organisation. <p align="center">Individual <input type="checkbox"/> Organisation <input checked="" type="checkbox"/></p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<i>Please use a new row for each comment and add extra rows as required.</i>	
6.1 Implications for policy	Enhanced training of general practitioners and physicians...	Coeliac UK supports this statement and recommends that identification of individuals at risk of coeliac disease in Primary Care should be given greater emphasis and be better resourced.	
6.2 Implications for research	Consideration should be given to undertake an RCT into the outcomes of screening for coeliac disease.	Coeliac UK supports this statement and emphasises the need for further research to inform and progress the screening agenda.	

2.

Organisation:			
Name:	David Sanders	Email address:	xxxxxxxxxxxx
<p>Please tick whether you are making this submission as an individual or on behalf of an organisation.</p> <p style="text-align: center;"> Individual <input checked="" type="checkbox"/> Organisation </p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<i>Please use a new row for each comment and add extra rows as required.</i>	
	Reactive coeliac disease is defined as; diagnosed auto-immune coeliac disease with persistent or recurrent malabsorption and atrophy of the bowel villi despite 6 to 12 months of a strict gluten free diet. The true prevalence is unknown but it is rare. It is treated with steroids and immunosuppressive drugs. It is associated with complications and mortality. ²²	Change reactive to refractory please	
	End of section 3: There is an agreed policy of diagnosis of patients presenting with clinical symptoms which would be relevant, but might need additional steps to reduce invasive interventions and avoid non adherence from people identified as positive when screened but who are asymptomatic.	please change compliance to adherence (there and anywhere else in the document). Due to the difficult connotations of compliance	