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# The long-term follow up of coeliac disease

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# Background

- Coeliac disease affects around 1% of adults in the UK (650k)
- But only 25-30% diagnosed
- Risks of adverse outcomes are small and minimal through adherence to a gluten free diet
- Suggestions regular review will improve adherence and thus enhance quality of life



# Follow up – the current picture

- Data lacking on how many receive follow up and nature of this – Coeliac UK 50%
- 34% of primary care sample not under follow up<sup>1</sup>
- Dietitian-led preferred, with doctor being available<sup>2</sup>

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pubmed/23623778> <sup>2</sup> <https://www.ncbi.nlm.nih.gov/pubmed/16556185>



## **1.4.3 Offer an annual review to people with coeliac disease:**

- *measure weight and height*
- *review symptoms*
- *consider the need for assessment of diet and adherence to the gluten-free diet*
- *consider the need for specialist dietetic and nutritional advice.*

## **1.4.4 Refer the person to a GP or consultant if concerns are raised in the annual review:**

- *the need for a dual-energy X-ray absorptiometry (DEXA) scan (in line with the NICE guideline on osteoporosis: assessing the risk of fragility fracture) or active treatment of bone disease*
- *the need for specific blood tests*
- *the risk of long-term complications and comorbidities*
- *the need for specialist referral.*

## Guidelines



### Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology

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#### ABSTRACT

A multidisciplinary panel of 18 physicians and 3 non-physicians from eight countries (Sweden, UK, Argentina, Australia, Italy, Finland, Norway and the USA) reviewed the literature on diagnosis and management of adult coeliac disease (CD). This paper presents the recommendations of the British Society of Gastroenterology. Areas of controversies were explored through phone meetings and web surveys. Nine working groups examined the following areas of CD diagnosis and management: classification of CD; genetics and immunology; diagnostics; serology and endoscopy; follow-up; gluten-free diet; refractory CD and malignancies; quality of life; novel treatments; patient support; and screening for CD.

last 8 years). As a result, the Clinical Services and Standards Committee of the BSG commissioned these guidelines, subject to rigorous peer review and based on a comprehensive review of the recent literature, including data from any available randomised controlled trials, systematic reviews, meta-analyses, cohort studies, prospective and retrospective studies.

A multidisciplinary panel of 18 physicians from eight countries (Sweden, UK, Argentina, Australia, Italy, Finland, Norway and the USA), a dietitian and a representative and a patient advocate from Coeliac UK reviewed the literature on the management of CD. These individuals were involved in the original stakeholder meetings and with revision of the manuscript.

#### Recommendations

- ▶ Diagnosis of CD requires duodenal biopsy when the patient is on a gluten-containing diet and for the vast majority of adult patients also positive serology. (Grade B)
- ▶ Biopsy remains essential for the diagnosis of

#### Intent and levels of evidence

All aspects of the contemporary diagnosis and management of patients with adult CD were considered. PubMed literature was searched from 1900 to 2012 to obtain evidence for these guidelines. Also there was input from all authors who have considerable expertise and experience in diagnosis and management of CD. The panel of international

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The management of adults with coeliac disease in primary care



<https://gut.bmj.com/content/gutjnl/63/8/1210.full.pdf>

<https://www.coeliac.org.uk/...primary-care-society-for-gastroenterology-2006/1pcsg-2.>

- No agreement – who, when or how?
- Less intensive versus more intensive – cost implications
- The evidence underpinning guidelines is weak
- Lack of insight from people living with coeliac disease and healthcare professionals involved in care



# Study aim

**To explore patients' and healthcare professionals' (HCPs) views and experiences on the long-term follow up of coeliac disease**



- Sample: individuals with coeliac disease and HCPs (gastroenterologists, general practitioners and dietitians)
- Data collection: semi-structured interview guides for each group
- Analysis: Framework approach



Individuals with coeliac disease	HCPs
Nature of follow up received	Importance of follow up
The purpose, the process and relation to attendance (non-attendance)	Current practices and procedures
Preferences for follow up	The most optimal follow up model



# Participant characteristics – patients

<b>N=50</b>	<b>n</b>	<b>%</b>
Age mean 54.5yrs (30-80yrs)		
Gender; Female	37	74
Ethnicity; White British	49	98
Employment; Employed	30	58
Not receiving follow up	30	60
Receiving follow up	16	32
Diagnosed <1yr	4	8

# Nature of follow up received and purpose

- Wide variation in process and regularity
- *'I'm not really sure what they're monitoring, they don't bother to tell me.'*
- Taking bloods and being weighed
- Not in line with guidelines

*I had a blood test and they asked 'are you all right?' and that was it*

*I have never been called in on a regular basis to see how I am managing*

*It was 6 monthly then yearly then every couple of years*



# The process and relation to attendance

- Positive aspects – point of contact, reassurance, bloods
- Not necessary for all
- Attend to ‘stay in the system’
- Negatives – repetitive

*I want to make sure everything's alright. Because obviously there can be other health complications...*

*I thought, why am I actually coming, what are you checking me for or what's the point of this? There didn't really seem to be one so I decided that I wouldn't go...*



# Preferences for follow up – location?

- For some, secondary care preferred
- But others primary care
- E-mail/telephone contact
- Seeing a knowledgeable person ('specialist') most important

*Hospital's better than GPs...GP's perhaps too general*

*GP surgeries are local to everybody and probably the ideal in terms of location*

*A health professional that understood coeliac, and would then put her, himself out to keep themselves up to date with what's going on*

# Preferences for follow up – when and content?

- Annually soon after diagnosis, but not for all
- Doing bloods important
- More individual basis
- More intensive to less intensive

*do not see what the value of being seen on an annual basis is*

*once a year to just touch base and just have my bloods checked*

*where people are looked at on an individual basis and not just a standard service for everybody*

*start with a one yearly appointment then two yearly then a five year review*



# Participant characteristics – HCPs

<b>N=43</b>	<b>n</b>	<b>%</b>
Age mean 44.1yrs (29-74yrs)		
Gender; Female	28	65
Ethnicity; White British	31	72
Gastroenterologist	10	23
General Practitioner	18	42
Dietitian	15	35



# Importance of follow up

- Generally HCPs thought served to reassure patients
- As medical necessity seen as less important
- More appropriate for certain groups

*It makes them feel like people are taking notice of their condition...it makes it easier for them to look after things themselves...*

*From a medical point of view, follow-up isn't always absolutely necessary...it probably makes a patient's life a lot easier*

*We should only be following up the ones that need to attend...it is beyond me in this day and age why we should follow up all*



# Current practices

- Practice is *'ad hoc' 'cobbled together'*
- Some follow NICE and BSG – others unaware or that it was unclear which HCP group they applied to
- Agreed by all HCPs that current process not sustainable

*A lot of us GPs were very confused as to what we were supposed to be doing in terms of following patients up*

*They suggest yearly follow up...they don't specify where that should happen*

*I don't know that we're going to be able to maintain it at that level (with increasing diagnoses)*



# The most optimal model

- Purpose of follow up and HCP roles need to be transparent
- Flexible, individualised and patient role needs taking into account, rather than a *‘one size fits all’* approach
- Underpinning factor is resources limited

*Need for standardisation of care across the country*

*The GP should do the blood test, but dietitians should have access to them and advise as appropriate*

*Their role is to take responsibility for their own healthcare*

*It's down to things like funding and what the service can actually provide*



# Comparing the two groups

- Purpose of follow up unclear among both groups
- Follow up serves to reaffirm and reinforce compliance = reassures people (blood tests valued)
- Perceived value and importance of follow up differed within groups



# Conclusions and the way forward

**Investigate what's currently being offered**

- Nature
- Regularity
- Costs
- How does this compare to guidelines?



**Identify, test and evaluate new models**



**Need for better guidelines**

- Delineate each HCPs' role
- Collaborative approach



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