

# Do gastroenterologists have medical inertia towards coeliac disease? A UK multicentre secondary care study

Matthew A Taylor ,<sup>1</sup> Rebecca J Blanshard,<sup>2,3</sup> Gregory Naylor,<sup>4</sup> Hugo A Penny,<sup>2</sup> Peter D Mooney,<sup>5,6</sup> David S Sanders<sup>1,2</sup>

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<sup>1</sup>The University of Sheffield Medical School, Sheffield, UK

<sup>2</sup>Academic Unit of Gastroenterology, Royal Hallamshire Hospital, Sheffield, UK

<sup>3</sup>The University of Sheffield, Sheffield, UK

<sup>4</sup>Chesterfield Royal Hospital NHS Foundation Trust, Chesterfield, UK

<sup>5</sup>Department of Gastroenterology, Northern General Hospital, Sheffield, UK

<sup>6</sup>Department of Gastroenterology, Leeds Teaching Hospitals NHS Trust, Leeds, UK

## Correspondence to

Professor David S Sanders; david.sanders1@nhs.net

## ABSTRACT

**Objective** This study aimed to assess if there is secondary care medical inertia towards coeliac disease (CD).

**Design** Group (1): Time from primary care presentation to diagnostic endoscopy was quantified in 151 adult patients with a positive endomysial antibody test and compared with 92 adult patients with histologically proven inflammatory bowel disease (IBD). Group (2): Across four hospitals, duodenal biopsy reports for suspected CD were reviewed (n=1423). Group (3): Clinical complexity was compared between known CD (n=102) and IBD (n=99) patients at their respective follow-up clinic appointments. Group (4): 50 gastroenterologists were questioned about their perspective on CD and IBD.

**Results** Group (1): Suspected coeliac patients waited significantly longer for diagnostic endoscopy following referral (48.5 (28–89) days) than suspected patients with IBD (34.5 (18–70) days; p=0.003). Group (2): 1423 patients underwent diagnostic endoscopy for possible CD, with only 40.0% meeting guidelines to take four biopsies. Increased diagnosis of CD occurred if guidelines were followed (10.1% vs 4.6% p<0.0001). 12.4% of newly diagnosed CD patients had at least one non-diagnostic gastroscopy in the 5 years prior to diagnosis. Group (4): 32.0% of gastroenterologists failed to identify that CD has greater prevalence in adults than IBD. Moreover, 36.0% of gastroenterologists felt that doctors were not required for the management of CD.

**Conclusion** Prolonged waiting times for endoscopy and inadequacies in biopsy technique were demonstrated suggesting medical inertia towards CD. However, this has to be balanced against rationalising care accordingly. A Coeliac UK National Patient Charter may standardise care across the UK.

## INTRODUCTION

Global meta-analysis of screening studies for coeliac disease (CD) has shown a variable prevalence of around 1%,<sup>1–4</sup> but the vast majority of these patients remain undiagnosed.<sup>1 5 6</sup> Comparison of screening studies with point prevalence data has demonstrated that only an estimated one in four cases of CD are diagnosed in the UK,<sup>5</sup> representing a significant undiagnosed burden. However, in other countries such as the USA, studies

## Summary box

### What is already known about this subject?

- ▶ Diagnostic delay is a key issue facing modern management of coeliac disease (CD) while only one in four cases are estimated to be diagnosed.
- ▶ Delayed diagnosis of CD is associated with an increased risk of complications from the disease and a worse quality of life.

### What are the new findings?

- ▶ Patients with CD face greater delays at all wait intervals from referral to diagnostic endoscopy compared with patients with inflammatory bowel disease (IBD).
- ▶ The majority of endoscopists do not follow guidelines for diagnostic endoscopy for CD. This reduced diagnosis rates by over 50%.
- ▶ Questionnaire findings presented an attitude of medical inertia towards CD alone and in comparison to IBD.
- ▶ This is the first study to fully represent how medical inertia towards CD directly leads to increased diagnostic delay and likely missed diagnoses.

### How might it impact on clinical practice in the foreseeable future?

- ▶ This study characterises and raises awareness of prominent medical inertia towards CD among secondary care clinicians and demonstrates the effects of this on diagnostic delay. Our findings advocate the need to combat this through lower thresholds for investigation, greater adherence to biopsy guidelines and increased referral urgency to reduce overall diagnostic delay.

have reported this undiagnosed burden to be far greater at 80%–90%.<sup>7 8</sup> There is variation between different nations in ability to detect the condition, with a particularly high level of confirmed diagnoses in Finland, as evidenced in the city of Tampere, where 0.75% of adults are diagnosed.<sup>1 9</sup>

Compounded with this undiagnosed burden, diagnostic delay is a key and widely reported issue facing modern management of CD.<sup>10–13</sup> Delays in diagnosis can present in



both primary and secondary care and international literature reports a mean delay range of 9.7–12.8 years.<sup>14–17</sup>

Of particular concern, these delays persist despite improvements in factors such as serological test availability, ease of access to endoscopy and increasing public awareness of the condition.<sup>5</sup> These long delays are especially worrying in context of the substantial improvement to quality of life associated with diagnosis.<sup>10 17</sup> Despite this burden of missed diagnoses and diagnostic delay, the incidence of CD continues to rise, with a fourfold increase in incidence seen in the UK between 1990 and 2011,<sup>5</sup> overall representing an increasing public health problem.

Delayed diagnosis of CD is correlated with increased risk of complications such as osteoporosis, peripheral neuropathy, microcytic (iron deficiency) and macrocytic (folate deficiency) anaemia, lymphoma (enteropathy associated T-cell lymphoma and other non-hodgkin lymphomas), hyposplenism, micronutrient deficiencies and increased rates of anxiety and depression.<sup>12 18</sup> Importantly, earlier diagnosis is associated with lower standardised mortality ratios,<sup>19 20</sup> while undiagnosed CD is associated with a worse quality of life which improves substantially on diagnosis.<sup>10 17</sup> Prompt management with a strict gluten-free diet (GFD) leads to a rapid reduction in symptoms and reduced risk of malignancy (specifically gastrointestinal carcinoma or lymphoma).<sup>12 18</sup>

Previous studies investigating the cause of such delay and undiagnosed burden have hypothesised reasons such as patient related factors,<sup>11</sup> to inability by clinicians to recognise the extraintestinal symptoms as indications for serological testing.<sup>8 21</sup> More recently, the focus on causes of delay has centred around clinician factors such as medical inertia towards the condition by primary care physicians and inadequacies in biopsy technique in diagnosis of the condition. A study of primary care physicians in the USA found only 60% would perform serological testing for a young caucasian man with unexplained IDA while 80% said they would start a serologically positive patient on a GFD prior to endoscopy. This suggests a failure to recognise the pervasiveness of CD and a lack of clinical knowledge in how to properly approach diagnosing the condition, suggesting a level of medical inertia towards it.<sup>22</sup> Meanwhile, studies examining previous endoscopies in patients with CD demonstrated a failure to complete biopsies or take an adequate number of biopsy samples despite presence of symptoms suggestive of CD prior to diagnosis, resulting in delayed diagnoses.<sup>23 24</sup>

In attempts to deal with these issues of delayed and missed diagnoses, guidelines for the management of CD are constantly updated to account for the evolving knowledge base on this disease. Current National Institute for Health and Care Excellence (NICE) guidelines recommend that patients referred with suspected CD have a duodenal biopsy within 6 weeks of referral and that the patient is strongly encouraged to eat gluten in more than one meal a day for at least 6 weeks before the

procedure.<sup>25</sup> This may prove problematic for patients who have self-diagnosed themselves with CD and are already abstaining from gluten. British Society of Gastroenterology (BSG) guidelines indicate that during diagnostic endoscopy at least four biopsy specimens should be taken, including a duodenal bulb biopsy.<sup>26</sup> This is in order to maximise diagnostic yield, as taking at least four biopsy specimens is shown to more than double the diagnostic rate in comparison to those undergoing less than four biopsies.<sup>24 25</sup> Whether these guidelines are adhered to in clinical practice remains an important question.

There is a lack of contemporary UK data assessing if there is still a delay in diagnosis. Moreover, reasons for delay are yet to be comprehensively explored. To refine the diagnostic pathway for CD, these factors must be characterised. The aim of this UK multicentre study was to assess the degree of delay present in the diagnostic referral pathway for CD as well as determine concordance with biopsy guidelines. Additionally, clinician attitudes towards CD were explored in an attempt to characterise the factors influencing delay.

## MATERIALS AND METHODS

### Group 1: primary care presentation to biopsy completion

All patients who registered a positive endomysial antibody (EMA) test in primary care and were then referred for an endoscopy over an 18-month period (04/2014–09/2015) in the South Yorkshire area were assessed for inclusion eligibility. The following data on each patient was collected: Hospital ID, Date of Birth, Gender, date of initial EMA positive blood test in primary care, date of referral to secondary/tertiary care, department referred to (gastroenterology, endoscopy, other), dates of interval appointments, date of endoscopy and Marsh Grade of duodenal biopsy specimens. For each patient, archived blood tests were examined to identify their first EMA positive result, which was recorded as the initial positive EMA result to be used in exclusion criteria. Patients were excluded if they were aged under 16, had a previously known diagnosis of CD, if the initial positive EMA result was requested by the gastroenterology outpatients department or other specialty (other than primary care) or if the patient never received a duodenal biopsy.

For the control group, all patients with a histological diagnosis of inflammatory bowel disease (IBD) following colonoscopy or flexible sigmoidoscopy were examined. The same data as those with histologically proven CD patients regarding dates of referral, appointments and endoscopy was collected and the same exclusion criteria applied. This selection criteria produced a cohort of 151 suspected CD patients and 92 IBD patients.

### Group 2: adherence to biopsy guidelines in detection of CD

Endoscopy and histology reports for all patients who had a duodenal biopsy for suspected CD in a 3-month period (11/2012–01/2013) in four UK hospitals were retrospectively reviewed. Indications for biopsy, number

of specimens received by histopathology, biopsy technique (single bite vs double bite), job roles of the endoscopist (physician, surgeon or nurse endoscopist) and final diagnosis were recorded for this cohort of 1423 patients. Findings of villous atrophy were required for diagnosis of CD. Of those subsequently diagnosed with CD, patient records were checked for any previous non-diagnostic gastroscopies (describing a gastroscopy where no biopsy samples were taken) in the 5 years prior to diagnosis. Patients were excluded if they had known CD.

### Group 3: case complexity analysis

An observational study was completed to compare patients attending a specialist CD clinic in a central teaching hospital (n=102) against patients attending a specialist IBD service in a central teaching hospital (n=99) and a control group of CD patients attending a general gastroenterology clinic at a district general hospital (n=36). All clinics were assessed over a 6 month period (09/2015–02/2016). This additional study analysed clinic appointment complexity. Both specialist clinics were exclusively follow-up appointments. Data regarding patient presenting symptoms, investigations (bloods, imaging, endoscopies, other), medications, referrals completed and planned follow-up periods was collected from clinic appointments.

### Group 4: gastroenterology clinicians' perspective

A questionnaire (completed between 2014 and 2015) aimed at assessing clinician attitudes towards CD was formed through use of a focus group consisting of a range of clinicians specialised in gastroenterology. Discrete choice experiments were used to establish clinician preferences using multiple options and ranking for interventions and service provision in the comparison of CD with Crohn's disease and ulcerative colitis (UC). Direct questioning (yes or no) was used to determine if the opinions of the focus group matched those gastroenterology clinicians.

A proforma (see online supplemental file) was completed through discussions with 50 gastroenterology registrars and consultants from across the UK. While questions from the proforma were asked directly, there was opportunity for discussion over specific options in order to generate qualitative data on clinician perspectives. Staff grades and specialist interests of clinicians completing the survey were also recorded.

## RESULTS

### Group 1: primary care presentation to biopsy completion

#### Time from referral to endoscopy

Time from referral to endoscopy was 48.5 (28–89) days for CD patients from both centres combined. This was significantly longer than the wait for suspected IBD patients (34.5 (18–70) days;  $p=0.003$ ).

### Biopsy grade

Longer delays to diagnosis correlated with a significantly decreased Marsh Grade of duodenal biopsies. Of those seen within 4 weeks, 15.5% had normal-borderline (Marsh grade 0–3a) histology results, compared with 44.9% seen after 4 weeks ( $p=0.017$ ).

### Group 2: adherence to biopsy guidelines in detection of CD

Of the 1423 patients that underwent duodenal biopsy, 97 (6.8%) of these were subsequently diagnosed with CD. Regarding biopsy guidelines, 40.0% the total number of patients who underwent diagnostic endoscopy had at least four biopsies taken. The median number of biopsies taken per patient was 3. If guidelines to take at least four biopsy samples were followed, diagnosis of CD was more likely than if three or less biopsy samples were taken (10.1% vs 4.6%  $p<0.0001$ ). While the median number of biopsies was greater in patients diagnosed with CD (4 vs 3  $p<0.0001$ ).

Of the patients that received a CD diagnosis following biopsy, 12.4% had received at least one non-diagnostic gastroscopy in the 5 years prior to diagnosis. When assessing endoscopist job roles, gastroenterologists and nurse endoscopists were significantly more likely than surgeons to follow guidelines (41.5% vs 51.2% vs 18.2%  $p<0.0001$ ) and therefore took at greater number of biopsies (3 vs 4 vs 2,  $p<0.0001$ ). Thus, gastroenterologists and nurse endoscopists made a diagnosis of CD in more cases than surgeons (7.1% vs 6.7% vs 3.0%,  $p=0.10$ ). The use of single bite biopsy technique compared with double bite resulted in an increase of 3 to 4 biopsies ( $p=0.02$ ) taken from the second part of the duodenum (D2).

### Group 3: case complexity analysis

Analysis of case complexity data (table 1) showed there was no significant difference in the number of times each presenting complaint was discussed and in the mean number of presenting complaints reported per patient between the CD group and the general clinic control group. When using the Bonferroni correction, the only symptom which specialist IBD patients experienced significantly more than specialist CD patients was bleeding (PR/in stool).

When comparing the two specialist clinics the following investigations were requested significantly more in the CD clinic than in the IBD clinic: blood tests, genetic testing, gastroscopy and dual energy x-ray absorptiometry (DXA) scans (table 2). When using the Bonferroni correction to adjust for multiple analysis the p values remained less than 0.05, and therefore, remained significant. When using the Bonferroni correction, no investigations were requested for more patients in the IBD group compared with the CD group.

Table 3 shows that when using the Bonferroni correction there was no significant difference between the amount of times each medication type was prescribed between the CD and general clinic group. When comparing the CD and IBD groups, a significantly greater

**Table 1** Presenting symptoms at follow-up clinic appointments

	Coeliac, %	IBD, %	P value	Adjusted P value	General, %	P value	Adjusted P value
<b>Abdominal pain</b>	36 (35.3)	45 (45.5)	0.142	–	8 (22.2)	0.148	–
<b>Diarrhoea</b>	37 (36.3)	52 (52.5)	<b>0.020</b>	0.18	9 (25.0)	0.217	–
<b>Stool urgency</b>	6 (5.9)	11 (11.1)	0.183	–	0 (0)	0.878	–
<b>Bloating</b>	20 (19.6)	11 (11.1)	0.095	–	6 (16.7)	0.698	–
<b>Bleeding (PR/in stool)</b>	5 (4.9)	18 (18.2)	<b>0.003</b>	<b>0.027</b>	2 (5.6)	0.137	–
<b>Nausea/vomiting</b>	8 (7.8)	1 (1.0)	0.721	–	2 (5.6)	0.089	–
<b>Headache</b>	13 (12.7)	11 (11.1)	<b>0.019</b>	0.171	1 (2.8)	0.649	–
<b>Weight loss</b>	12 (11.8)	2 (2.0)	<b>0.007</b>	0.063	2 (5.6)	0.289	–
<b>Fatigue</b>	9 (8.8)	7 (7.1)	0.647	–	3 (8.3)	0.928	–

Bold denotes a significant value with  $p < 0.05$ .

IBD, inflammatory bowel disease; PR, per rectum.

number of patients were prescribed immunosuppressive medication, disease-modifying antirheumatic drugs and anti-inflammatory medication.

#### Group 4: gastroenterology clinicians' perspective

Of those completing the questionnaire, 64.0% (32) were registrar grade (trainee) and 36.0% (18) were consultants.

Questionnaire results revealed that 32.0% (16) of gastroenterologists failed to identify that CD has greater prevalence in adults than IBD. 36.0% (18) of gastroenterologists felt that doctors were not required for the management of CD while 16.0% (8) felt that a diagnosis of CD does not significantly impact patient quality of life.

Additionally, 40.8% (20) said that management of CD is not academically challenging. 88.0% (44) believed CD was less difficult to manage than IBD while 82.0% (42) thought CD was less significant than IBD in terms

of resources needed to diagnose and treat. 77.1% (37) thought CD had less of an impact on quality of life than IBD.

Discussion of proforma answers with clinicians gave rise to a number of common themes based on perspectives of CD and IBD (table 4).

#### DISCUSSION

This contemporary multicentre UK study demonstrates prolonged waiting times for endoscopy and inadequacies in biopsy technique for adult patients with suspected CD. This objectively suggests medical inertia towards CD among secondary care clinicians.

Endoscopy waiting times were not in keeping with NICE guidelines of 6 weeks.<sup>25–27</sup> There was a significant negative correlation between delay till endoscopy and Marsh Grade of biopsy. This may suggest that with

**Table 2** Investigations at follow-up clinic appointments

	Coeliac	IBD	P value	Adjusted P value	General	P value	Adjusted P value
<b>Bloods</b>	83 (81.4%)	43 (43.4%)	<b>&lt;0.001</b>	<b>&lt;0.001</b>	26 (72.2%)	0.247	–
<b>Genetic testing</b>	13 (12.7%)	0 (0%)	<b>&lt;0.001*</b>	<b>0.002</b>	3 (8.3%)	0.562*	–
<b>Gastroscopy</b>	21 (20.6%)	1 (1.0%)	<b>&lt;0.001</b>	<b>&lt;0.001</b>	6 (16.7%)	0.610	–
<b>Colonoscopy</b>	7 (6.9%)	16 (16.2%)	<b>0.038</b>	0.38	1 (2.8%)	0.680*	–
<b>Flexible sigmoidoscopy</b>	1 (1.0%)	3 (3.0%)	0.364*	–	0 (0%)	1.000*	–
<b>Capsule endoscopy</b>	2 (2.0%)	5 (5.1%)	0.274*	–	0 (0%)	1.000*	–
<b>Imaging</b>	4 (4.0%)	10 (10.1%)	0.085	–	1 (2.8%)	1.000*	–
<b>SeHCAT test</b>	2 (2.0%)	2 (2.0%)	1.000*	–	0 (0%)	1.000*	–
<b>DXA scan</b>	15 (14.7%)	0 (0%)	<b>&lt;0.001</b>	<b>&lt;0.001</b>	5 (13.9%)	0.905	–
<b>Breath tests</b>	2 (2.0%)	3 (3.0%)	0.678*	–	0 (0%)	1.000*	–
<b>Mean number of investigations (±SD)</b>	2.19 (±1.41)	1.93 (±1.35)	<b>&lt;0.001</b>	–	1.44 (±1.23)	0.054	–

Bold denotes a significant value with  $p < 0.05$ .

\*One or more of the cells in 2x2 table have an expected count  $< 5$ , Fisher's exact test is used to calculate p values.

DXA, dual energy x-ray absorptiometry; IBD, inflammatory bowel disease; SeHCAT, selenium homocholic acid taurine.

**Table 3** Prescribed medications at clinic appointments

	Coeliac, %	IBD, %	P value	Adjusted P value	General, %	P value	Adjusted P value
<b>Steroid</b>	16 (15.8)	21 (21.2)	0.312	–	0 (0)	<b>0.012*</b>	0.084
<b>Immunosuppression</b>	16 (15.8)	38 (38.4)	<b>&lt;0.001</b>	<b>0.002</b>	1 (2.8)	<b>0.043*</b>	0.301
<b>DMARD</b>	1 (1.0)	21 (21.2)	<b>&lt;0.001</b>	<b>&lt;0.001</b>	0 (0)	1.00*	–
<b>Anti-inflammatory</b>	0 (0)	19 (19.2)	<b>&lt;0.001</b>	<b>&lt;0.001</b>	0 (0)	1.00*	–
<b>Antispasmodic</b>	5 (5.0)	1 (1.0)	0.212*	–	0 (0)	0.326	–
<b>Sequestrant</b>	2 (2.0)	2 (3.0)	1.00*	–	0 (0)	1.00*	–
<b>Other</b>	11 (10.9)	11 (11.1)	0.820*	–	1 (2.8)	0.288	–

Bold denotes a significant value with  $p < 0.05$ .

\*One or more of the cells in 2x2 table have an expected count  $< 5$ , Fisher's exact test is used to calculate p values.

DMARDs, disease-modifying antirheumatic drugs; IBD, inflammatory bowel disease.

greater wait time patients are more likely to self-impose a GFD, likely in attempt to achieve the improved quality of life from switching to a GFD,<sup>10 17 28</sup> and increasing the chance of a missed diagnosis. However, there is as of yet no empirical evidence in the literature that greater delays till diagnosis mean patients are more likely to self-initiate a GFD. This is an area that warrants further investigation. It could be argued that instead those patients with a more florid histology were likely to be more symptomatic so were prioritised earlier for endoscopy. However, when grading urgency of endoscopy referrals in the UK, gastroenterologists usually only have the information provided on the referral letter.

The fact that in only 40.0% of endoscopies four biopsy samples were taken clearly represents how in the majority of duodenal biopsies BSG guidelines are not followed.<sup>26</sup> The detriment from this is clearly shown through the greater than doubled diagnosis rate (10.1% for four or more biopsies vs 4.6% for three or less) seen in endoscopies where the guidelines were followed. This is a clear example of the impact of diagnostic inertia towards CD on missed or delayed diagnoses and is backed by a similar low rate of guideline adherence (35%) in a USA based biopsy study.<sup>24</sup> Patients with missed CD will go on to experience more harm through possible repeat endoscopies and more time spent following a gluten containing diet. To build on this, 12.4% of the patients diagnosed with CD

had received a previous non-diagnostic (here meaning that no biopsy samples were taken) gastroscopy in the 5 years before their diagnosis.

A strong majority of 88.0% rated IBD as having greater complexity than CD and 82.0% believed CD was less significant than IBD in terms of resources needed to diagnose and treat. Furthermore, 36.0% of clinicians felt that doctors are not required for management of CD and 40.8% believed management of CD was not academically challenging. These findings suggest significant proportions of gastroenterology clinicians believe CD should be treated with less urgency than IBD and that it is not a condition for which medical expertise is required, further building a picture of medical inertia towards the condition.

A systematic review estimated prevalence of 0.005%–0.5% for UC and 0.0006%–0.32% for Crohn's disease in Europe.<sup>29</sup> However, 32.0% of clinicians incorrectly identified IBD as having greater prevalence than CD. A previous study compared Crohn's disease, UC, CD patients and healthy controls using the Short-Form 36-Item Health Survey and the Hospital Anxiety and Depression Scale to determine quality of life scores. The total study population was 1031, with over 200 patients included for each condition. Although Crohn's disease patients reported the worst scores for general health, UC patients reported better general health than CD patients.<sup>30</sup> The influence

**Table 4** Key qualitative themes

Key qualitative themes	
1.	Some clinicians had the view that CD is commonly found incidentally and that the majority of patients are asymptomatic and do not require medical interventions.
2.	Most doctors believed that the input of a gastroenterologist is only required for confirming the diagnosis of CD. They suggested that all coeliac patients should then be managed in the community or by a dietitian.
3.	It was often suggested that the impact on a coeliac patient's quality of life is due to their dietary restrictions and lifestyle changes, rather than the burden of their symptoms. There was a suggestion that IBD patients suffer more from their symptoms.
4.	Doctors suggested that patients with severe and persisting symptoms have a worse quality of life than those with IBD, however, in their opinion, there were few patients with significant symptoms of CD compared with those with IBD.

CD, coeliac disease; IBD, inflammatory bowel disease.

of diet on social interaction is well characterised and it has been shown patients with CD feel negatively controlled by their dietary restrictions, causing a significant impact on their social relationships<sup>31</sup> in addition to their physical symptoms. The economic impact of purchasing gluten free products, which can be an average of 4.1 times more expensive and much less available than their gluten containing counterparts is also well recorded, providing an example of the continuing impact of the condition even following effective treatment.<sup>32</sup>

Despite this, 77.1% of gastroenterologists questioned believed CD had less of an impact on patient quality of life than both Crohn's disease and UC. Moreover, 16.0% of gastroenterologists believed CD caused no significant impact on quality of life. This is a significant proportion considering the specialism of those surveyed and the presence of numerous studies characterising the effect of CD on patient quality of life.<sup>10 17 28</sup> Furthermore, our follow-up appointment observational findings demonstrate similar frequencies of symptom presentation between specialist CD and IBD clinics, with only significantly greater (following Bonferroni correction) bleeding (PR/in stool), in patients with IBD. In this context, our findings clearly exhibit medical inertia towards CD, showing medical professionals do not appreciate the impact of the condition both alone and in comparison to similar conditions.

A recent study by Pritchard *et al* suggests that over 75% of CD patients have no primary care follow-up appointment,<sup>33</sup> despite the fact that telephone follow-up clinics have been shown to have a positive impact of GFD adherence in adults with CD.<sup>34</sup> This combined with the finding that 36.0% of gastroenterologists felt that doctors were not required for the management of CD and that 30% of all CD patients have non-responsive CD (defined as persisting symptoms despite being on a GFD),<sup>35</sup> suggests the need for an achievable, standardised national follow-up service for CD. Our recommendation is to call this 'Coeliac UK, National Patient Charter' and this would involve access to a dietitian as first point of contact, then access to a gastroenterologist if needed (e.g. a named gastroenterologist in every centre). This reflects findings on patient attitudes to follow up which demonstrated that the preferred method of follow-up for CD patients is to primarily see a dietitian but with the option to see a doctor also if required.<sup>36</sup>

Dietetic services in the UK have been demonstrated to be inadequately resourced, with the majority of trusts not providing specialist clinics,<sup>37</sup> and thus innovative methods for providing dietetic services are required such as group clinics,<sup>38</sup> telephone clinics or digital apps. If a pathway could be created that is achievable and economical for the whole of the UK then this system could be mandated by the Coeliac National Charity perhaps under the auspices of a patient charter.

The recent recommendation for a no biopsy strategy for suspected CD patients with a 10-fold tissue transglutaminase IgA serology (10-fold of the upper limit

of normal) may mitigate the delays for gastroscopy in approximately 25% of patients.<sup>39</sup> However, the remaining 75% may still be subject to the delays observed in this study unless the grading system is changed for this group of patients.

This is the first study to objectively demonstrate how medical inertia within secondary care causes diagnostic delay in the management of CD. We believe that comparing IBD and CD is akin to comparing apples and oranges and that this in essence is the crux of the issue. The medical inertia demonstrated by our study is likely due to the black and white view of IBD versus CD where all IBD cases are seen as apples needing urgent attention and all CD cases are oranges that are only referred down a routine pathway. Our findings suggest IBD and CD are not as different in clinical impact as they are treated. Improved knowledge of the clinical significance of CD may lead to more balanced referral grading among secondary care clinicians. Greater adherence to biopsy guidelines will produce higher diagnosis rates. These changes will contribute to reducing the vast undiagnosed burden of CD by producing more prompt diagnoses, resulting in better health outcomes.

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#### ORCID iD

Matthew A Taylor <http://orcid.org/0000-0002-1474-8920>

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