



# All-Party Parliamentary Group on Coeliac Disease

Diagnosing Coeliac Disease:  
Optimising the Pathway for  
Improved Patient Outcomes

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## The APPG on Coeliac Disease:

The All-Party Parliamentary Group on Coeliac Disease is a backbench cross-party group of MPs and Peers in the UK Parliament.

The All-Party Parliamentary Group (APPG) on Coeliac Disease was re-established in 2022, with the purpose of meeting to discuss, develop, and promote policy solutions to improve the lives of the coeliac community across the United Kingdom.

The group aims to raise awareness of coeliac disease to ensure that those with the condition receive the best possible care to live happier, healthier lives. Coeliac disease is a common, serious autoimmune condition, estimated to affect 1 in every 100 people living in the UK. It's triggered by gluten ingestion, a protein found in wheat, barley and rye, and some people are sensitive to avenin in oats too. It results in damage to the intestinal lining and symptoms are diverse and vary in severity. Symptoms can include diarrhoea, constipation, extreme tiredness, recurrent mouth ulcers, weight loss and bloating. Left undiagnosed and untreated it can cause complications such as anaemia, osteoporosis, issues with fertility and neurological conditions and in rare cases small bowel lymphoma. In the UK only 1 in 3 people with coeliac disease have a medical diagnosis, meaning there are almost 500,000 people living with undiagnosed coeliac disease, experiencing the associated symptoms affecting their everyday life. The only current treatment for coeliac disease is a strict gluten free diet for life. Simple activities like food shopping and eating out, can become a chore when you cannot eat gluten. In raising awareness about coeliac disease, there is a hope that the Group can reduce the current, average 13 years from onset of symptoms to diagnosis for adults, and work with policy makers and the food industry to create better and wider access to affordable gluten free food.

As well as providing a forum for MPs and Peers, the Group aims to bring clinicians, patients, and other relevant stakeholders together to discuss coeliac disease.

### APPG Membership - Parliamentary Officers

- Co-Chair & Registered Contact – Sharon Hodgson MP, Labour
- Co-Chair – Baroness Bakewell of Hardington Mandeville MBE, Liberal Democrat
- Vice Chair – Jason McCartney MP, Conservative
- Vice Chair – Jim Shannon MP, Democratic Unionist Party
- Vice Chair – Virendra Sharma MP, Labour
- Vice Chair – Rt Hon Kevan Jones MP, Labour
- Vice Chair – Ruth Jones MP, Labour

### The Inquiry:

The focus of the inquiry is to gather evidence from key clinical stakeholders through oral evidence sessions, to support a report and series of recommendations calling for better diagnosis of those living with coeliac disease.

## Foreword from the Chairs

**Coeliac disease is a serious autoimmune condition** caused by a reaction to gluten, found in wheat, barley and rye. Symptoms are wide ranging but can include bloating, stomach cramps, vomiting, diarrhoea and extreme tiredness. Extraintestinal symptoms are diverse and include anaemia, low bone density, skin rashes, loss of balance, sensory symptoms, cognitive slowing, anxiety and depression.

There is no cure for the condition and the only treatment is a strict gluten free diet for life. **Undiagnosed and therefore untreated coeliac disease can lead to the development of long term associated conditions such as osteoporosis, neurological dysfunction, fertility problems, and in rare cases small bowel lymphoma.** It is not an allergy or intolerance, and it has nothing to do with a fad diet.

Coeliac disease affects 1 in 100 people across the UK, yet nearly two thirds of those living with the condition have yet to receive a diagnosis. This translates to potentially **500,000 people in the UK, living and suffering avoidable harm due to undiagnosed coeliac disease.** Studies show that 80% of children with coeliac disease are currently undiagnosed across the UK.

Half a million people are potentially feeling unwell, being put at risk of long-term health conditions and going through unpleasant, and crucially unnecessary investigations. **This is damaging for the individual, the health service and society as a whole.**

**On average it takes an adult an alarming 13 years from onset of symptoms to obtain a diagnosis. One in 4 are misdiagnosed with Irritable Bowel Syndrome (IBS) despite NICE guidance recommending coeliac disease is ruled out before any such diagnosis is made. Over 50% of those who answered the APPG's Call to Evidence thought the length of endoscopy waiting times had an impact on coeliac disease diagnosis.**

The numbers diagnosed must be increased and the time it takes for a patient to receive a diagnosis shortened.

As part of a series of evidence sessions, the APPG heard from healthcare professionals (HCPs) with expertise in coeliac disease from across primary and secondary care, patients and researchers. The challenges were many and the impact, on both patient population and the health service, significant. However, we also heard of **many opportunities to overcome these challenges, to the benefit not just of those with coeliac disease, but the wider healthcare system too.**

The APPG believes through several system wide changes, patients' quality of life can be improved, and the long-term management of the condition simplified. This will help to reduce the strain on NHS services and HCPs themselves.

In the report, we look at the case for supporting better diagnosis in primary care through incentivisation, training of GPs and allied healthcare professionals (AHPs), lowering the thresholds to serological testing, adoption of dietetic-led pathways, a no biopsy strategy and public awareness raising.

By following the recommendations laid out in this report and finally tackling the underdiagnosis of coeliac disease, **the NHS can better provide patients with the care and support they need sooner and, crucially, reduce the unnecessary appointments and investigations that harm both the individual and waste valuable resources within the system.**

We thank all those who took part in these sessions and contributed to our findings and look forward to working with the Government and NHS leaders to take the recommendations in the report forward.



**Sharon Hodgson MP**  
(Co-chair APPG on Coeliac Disease)



**Baroness Bakewell of  
Hardington Mandeville MBE**  
(Co-chair APPG on Coeliac Disease)

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## Executive Summary

The APPG has heard from a range of key stakeholders including patients and HCPs, regarding the barriers to prompt diagnosis of coeliac disease and the impact this poses to the patient and the health service. Four online evidence sessions were held covering the following themes:

- Supporting primary care to better identify coeliac disease
- The diagnosis pathway- earlier recognition and improved time to diagnosis
- Public awareness
- Ensuring effective examination of undiagnosed and misdiagnosed people living with coeliac disease.

Alongside these sessions, the APPG also held a call to evidence, inviting HCPs and patients to share their experience of the diagnosis pathway via an online survey. We received 120 responses. The APPG wishes to thank all those that took part.

### The APPG found that:

- **Knowledge of the condition and its symptoms in primary care is low.** Polling of GPs by Coeliac UK found that only 25% knew the prevalence of coeliac disease is 1 in 100, whilst 38% believed it to be 1 in 10,000. Over a third (37%) did not know that gluten needed to be in the diet for a minimum six weeks before taking a blood test to measure the antibodies associated with coeliac disease.<sup>1</sup> This risks the potential for a false negative result if gluten is reduced or removed from the diet prior to testing.
- While a range of primary care professionals play a role in the diagnosis of coeliac disease, **the APPG has highlighted the significant role that pharmacists could contribute due to the way patients present with symptoms.** The APPG heard that pharmacists were previously given training on coeliac disease through partnered working between the Centre for Pharmacy Postgraduate Education (CPPE) and Coeliac UK.<sup>2</sup> However, this learning tool is now out of date and no longer provides educational materials for pharmacists.<sup>3</sup> Like other HCPs, pharmacists need protected time to carry out training to better understand the diagnosis of coeliac disease.
- **Even where knowledge exists, there is little incentive to diagnose or proactively case find.** Coeliac disease is not recognised within the Quality and Outcomes Framework (QOF) or the commissioning for Quality and Innovation Framework, and as such there is little financial incentive for low thresholds to test for the condition.<sup>4</sup> Similarly, as part of the Community Pharmacy Contractual Framework (CPCF), pharmacy quality schemes were introduced to reward community pharmacies for delivering a set criteria on clinical effectiveness, patient safety, and patient experience.<sup>5</sup> These schemes outline training requirements for pharmacists with timely deadlines, yet this does not properly take account of coeliac disease. Lack of incentives makes it hard for a practice to justify proactively targeting case finding within the community through audits or awareness raising activities.
- **The diagnostic pathway for coeliac disease varies across the country with divergent levels of care and a failure to adopt best practice.** Those with suspected coeliac disease face long waits for endoscopy, a necessary requirement for the majority to receive a diagnosis. Over 50% of those who answered the Call to Evidence thought the length of endoscopy waiting times had an impact on coeliac disease diagnosis, with many noting the long-term health implications of delayed diagnosis. A no biopsy strategy, currently in place for children, was recommended for adults under the interim British Society of Gastroenterology (BSG) guidance during the Covid-19 pandemic. This recommends that patients who are under 55 years of age, with suspected coeliac disease and an IgA tissue transglutaminase (tTG) level 10x higher than normal can be diagnosed through serological tests without the need for biopsy.<sup>6</sup> However, the APPG has heard that despite reducing the pressure on endoscopy waiting lists, its implementation has been piecemeal and sporadic across the UK.

**A survey on patients with coeliac disease found that 65% of patients' first choice would be to see a dietitian, with 80% of those requesting a specialist dietitian.<sup>7</sup>**

- **Dietitians play a crucial role in the diagnosis of coeliac disease and are the experts in the management of the condition.**

A survey on patients with coeliac disease found that 65% of patients' first choice would be to see a dietitian, with 80% of those requesting a specialist dietitian.<sup>7</sup> The APPG heard examples of excellent dietetic-led services in parts of the UK. These models have been shown to save money, with savings and benefits to patients' quality of life shown in the long-term.<sup>8</sup> However, such services have been deployed inconsistently leading to variation in how services operate across England and the UK.

- **According to a recent YouGov poll, nearly 1 in 5 people (19%) did not know or recognise any of the listed symptoms of coeliac disease.** There was also a statistically significant difference in the lack of awareness of coeliac disease between different social grades (ABC1-middle=23%, C2DE-working =31%). This poses a significant barrier to individuals presenting to appropriate HCPs<sup>9</sup>

In response to these challenges, the APPG has identified several recommendations that it feels could have a real impact.

### **Improve understanding of coeliac disease and its symptoms amongst HCPs**

NHS England and Government should:

- Support the dissemination of key messaging to GPs and pharmacists on coeliac disease and the need for early diagnosis.
- Support the development of a coeliac disease training programme for primary care physicians and other Allied Health Professionals (AHPs) so that they can better understand the complex nature and diverse manifestations of coeliac disease.
- Encourage GPs to approach coeliac disease with a low threshold for testing and recognise the varied symptoms associated with the condition.
- Provide pharmacists with tailored education and support tools to assist in the diagnosis of coeliac disease in primary care.
  - As a crucial part of the system, the awareness of coeliac disease in pharmacies needs to be improved. Tailored educational materials should be developed to meet the needs of pharmacists and support their ongoing work commitments.

### **Incentivising case finding**

NHS England and Government should:

- Improve incentivisation in primary care to follow existing NICE guidelines<sup>10</sup> on coeliac disease.
  - Medical professionals need to be given more support to follow guidance which outlines the pathway for diagnosing coeliac disease in primary care settings.
  - QOF and Quality and Innovation Frameworks should reflect the benefits of early diagnosis of coeliac disease and reward best practice.
- Implement support mechanisms to assist HCPs in primary care to carry out clinical audits.
  - It is important HCPs are given allocated time to carry out clinical audits to further the clinical understanding of coeliac disease and support the sharing of best practice across the country.

### **Developing unified clinical pathways (No-biopsy and dietetic-led services)**

NHS England and Government should:

- Support the adoption of dietetic-led services across the country.
  - This will allow patients to be referred to a dietitian who can provide specialist knowledge to empower patients to manage their condition as they move along the pathway to receive a diagnosis, and where appropriate adopt a no-biopsy route to diagnosis.
- Commit to adoption of a unified diagnostic pathway for lower GI symptoms in primary care.
- Work with professional bodies such as the British Dietetic Association and British Society of Gastroenterology to promote the relationship between dietitians and gastroenterologists to better support the long-term management of patients with coeliac disease.
- Develop coeliac endoscopy lists, prioritising those with suspected coeliac disease so that these patients' cases can be resolved quicker, therefore relieving pressure on the system.
- Support further research into the efficacy of dietetic-led clinics and support expansion of their use in England.

### **Raising awareness amongst the general public**

NHS England and the Government should:

- Develop a public health campaign to raise awareness of coeliac disease and its symptoms.
  - This could be done through educational materials such as posters and leaflets in hospitality venues, GP practices and pharmacies.
- Link up with HCP champions and Coeliac UK to support existing public awareness campaigns such as Coeliac UK's Awareness Week.

It is the APPG's view that addressing the challenge of underdiagnosis of coeliac disease should be a key priority for the Government and NHS England. By developing new and engaging education resources and training for GPs and Pharmacists, we can ensure primary care is equipped to spot the signs of coeliac disease earlier, reducing the risk of misdiagnosis. By incentivising case finding within the community through dissemination of audit tools and better incentives in primary care, we can free more people from the uncertainty of their illness.

Great work is taking place across the UK and the APPG has heard of best practice in the form of dietetic-led clinics and the implementation of the no-biopsy strategy. This needs to be shared and implemented across the service. A big part of this can be delivered through the development and implementation of unified clinical pathways for coeliac disease. Examples of this include the Scottish coeliac pathway or the ongoing work to develop a single clinical pathway for gastrointestinal (GI) symptoms in primary care. The Government and NHS leadership should engage with this work, and we encourage them to support the sharing of best practice laid out in this report. Finally, it must be recognised that one of the most significant barriers to diagnosis can occur before a patient has even come into contact with the health service. Public awareness of coeliac disease and its symptoms needs to improve in order to tackle the challenge of underdiagnosis and so we are calling on the Government and NHS to support the development of a public awareness campaign to highlight the varied symptoms associated with the condition and the importance of an early diagnosis.

By addressing the recommendations in this report, ensuring our HCPs have the knowledge and tools at hand, that clinical pathways are in place and public awareness is high, we believe more people can and will be diagnosed sooner, meaning fewer wasted resources and less unnecessary suffering for the patient.

## Introduction

Coeliac disease is a serious autoimmune condition that affects 1 in every 100 people. Symptoms are wide ranging but can include bloating, stomach cramps, vomiting, diarrhoea and extreme tiredness. Extraintestinal symptoms can be diverse and include anaemia, low bone density, skin rashes, loss of balance, sensory symptoms, cognitive slowing, anxiety, and depression.

There is no cure for the condition and the only treatment is a strict gluten free diet for life. **Undiagnosed and therefore untreated coeliac disease can lead to the development of long-term associated conditions such as osteoporosis, neurological dysfunction, fertility problems, and in rare cases lymphoma and small bowel cancer.**

Yet, despite the significant risks associated with untreated coeliac disease, nearly two thirds of all those with the condition have yet to receive a diagnosis and on average it takes an adult 13 years from onset of symptoms to be diagnosed. Misdiagnosis is common, with a significant number of patients with coeliac disease (1 in 4) having been previously misdiagnosed with Irritable Bowel Syndrome (IBS).

This report explores the challenges faced by people living with undiagnosed coeliac disease and the critical role of HCPs across primary and secondary care settings, in facilitating timely and accurate diagnoses. It looks at the opportunities available to confront shortcomings within the system and makes the clear case that addressing these will benefit not only the coeliac community but the wider health service, its staff, and beneficiaries too.



## Chapter 1: Diagnosing Coeliac Disease - The Current Landscape

People living with undiagnosed coeliac disease often present in primary care and begin their diagnosis journey at this point. If a GP suspects that a patient has coeliac disease, a blood test should be arranged to check for antibodies, with the patient told to keep gluten in their diet.<sup>11</sup> If antibodies are found in the patient's blood, the GP should then refer them to a gastroenterologist, a specialist in stomach and bowel conditions.<sup>12</sup>

A gastroenterologist will perform an endoscopy and biopsy to help confirm a diagnosis. This involves a small camera called an endoscope being passed through the mouth and stomach into the gut. It is done using an anaesthetic spray to numb the throat, or with a sedative given by injection. During biopsies, small pieces of gut tissue are collected and examined under a microscope to check for damage to the gut lining (villous atrophy), which is typical of coeliac disease.<sup>13</sup>

In contrast to adults, a no-biopsy approach to diagnosing coeliac disease in children has been in place since the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) recommended its use in 2012.<sup>14</sup> In 2020, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) updated recommendations on a no-biopsy approach for diagnosing coeliac disease in children who meet certain requirements.<sup>15</sup> It is important to note that while a no-biopsy approach is recommended for children, this is not always followed, and a biopsy should still be performed on children with a positive IgA tissue transglutaminase antibody test (IgA tTG) but with lower titres/levels (<10 times upper limit of normal). Diagnoses in children should be carried out by either a paediatrician with an interest in gastroenterology or a paediatric gastroenterologist, to support children and their families with specialist care. Children, in addition to having typical gut symptoms, may also present with a variety of other symptoms, including faltering growth, static weight, or progressive weight loss.<sup>16</sup>

Currently interim guidance from the British Society of Gastroenterology (BSG) published during the pandemic recommends a no biopsy approach for adult patients who are under 55 years of age, with suspected coeliac disease and an IgA tTG antibody level 10x higher than normal.<sup>17</sup> The APPG heard evidence estimating around 20% of adult patients could benefit from the use of a no-biopsy strategy.<sup>18</sup> The BSG is expected to publish updated guidance later this year, in place of the interim guidance, including recommendations for the safe use of a no-biopsy policy for adults.

The range of primary care professionals who can have a role in the diagnosis of coeliac disease varies from GPs, nurses, pharmacists, and paramedics.<sup>19</sup> This means the pathway for diagnosis can be complex with patients reaching the NHS through a variety of different touch points.





## Chapter 2: The Need for Improved Training, Particularly in Primary Care

As established, primary care is often the first touch point for an individual with undiagnosed coeliac disease. It is therefore vital that HCPs in these settings are equipped and incentivised to accurately diagnose coeliac disease in a timely manner. Among primary care professionals, pharmacists and GPs play a crucial role in the diagnosis of coeliac disease.

Awareness of the condition, amongst the general population, is often poor, and whilst more newly qualified HCPs have the benefit of updated knowledge of the condition, many longer serving practitioners are still working on an outdated understanding of the condition. The APPG heard from Coeliac UK about its experience of polling GPs at a 2021 training event (Figure 1.) Concerningly, only 25% of those in attendance correctly recognised the prevalence of the condition as 1 in 100, whilst 38% believed it to be 1 in 10,000, effectively considering coeliac disease to be a rare disease.

Of further concern, is that more than 1 in 3 GPs were unaware of the need to keep gluten in the diet for six weeks prior to taking a blood test for coeliac disease. Failure to do so poses significant risk of a false negative result, potentially providing a misleading outcome for the patient. In more positive findings, the charity found that following the training session, the number of GPs indicating to be 'not very confident in identifying and testing for coeliac disease', had reduced from 56% from the start to the session to only 7%, showing the impact Continued Professional Development (CPD) sessions can have.<sup>20</sup>

### Figure 1: Poll results from the RCGP online webinar, July 2021; Practical training - Coeliac disease, the patient and the community experience

- Only 25% (1 in 4) recognised the prevalence of coeliac disease is 1 in 100 with 38% believing it to be 1 in 10,000.
- 32% did not expect the NICE guideline to include unexplained fertility as a condition associated with undiagnosed coeliac disease.
- Over a third (37%) did not know that gluten needed to be in the diet for a minimum of six weeks before taking a blood test to measure the antibodies associated with coeliac disease.
- At the start of the training session, 56% of GPs indicated that they were not very confident at identifying and testing for coeliac disease in primary care. At the end of the session this had reduced to only 7%.

These findings were further reflected in the evidence we heard from contributors to the APPG's oral evidence session on primary care, with a number of HCPs referring to the misunderstanding of the condition amongst GPs.<sup>21</sup> Furthermore, a study published in 2019 by Kim Chandler and Gerry Robins looked to determine whether case-finding of coeliac disease is better than random testing in primary care. Following an examination of referrals between December 2013 to November 2014, the researchers found that case-finding of coeliac disease patients in primary care is no better than random testing of the population. The study recommended that more education is needed for the population and primary care physicians on the symptoms of coeliac disease, so as to ensure better awareness for coeliac disease.<sup>22</sup>

Pharmacists can play a significant role in the diagnosis of coeliac disease and are often a key touch point for those with undiagnosed coeliac disease due to the way in which patients present with symptoms. Commonly, patients with minor gastrointestinal issues self-manage their symptoms with over the counter treatments available at pharmacies or supermarkets.<sup>23</sup> Pharmacists offer the unique opportunity to improve diagnosis rates of coeliac disease, due to their wide geographical spread and extended opening hours, allowing for more flexibility for patients.

The NHS Long Term Plan<sup>24</sup> re-emphasised NHS England's commitment to offering care closer to home. In the Plan, NHS England commits to enhancing the use of community pharmacists to make greater use of their skills and the opportunities present when engaging with patients. As with GPs, the APPG heard evidence that pharmacists often lack the knowledge and awareness of coeliac disease to accurately identify it.<sup>26</sup> The APPG therefore believes it is vital that pharmacists are given specific training to understand the wide range of symptoms associated with the condition. The APPG understands that previously pharmacists were given training on coeliac disease through partnered working between the Centre for Pharmacy Postgraduate Education (CPPE) and Coeliac UK. However, this learning tool is now out of date and no longer provides educational materials for pharmacists.

Like other HCPs, pharmacists need protected time to carry out training to better understand the diagnosis of coeliac disease. As part of the Community Pharmacy Contractual Framework (CPCF), pharmacy quality schemes were introduced to reward community pharmacies for delivering quality criteria across clinical effectiveness, patient safety, and patient experience. These schemes outline training requirements for pharmacists with timely deadlines.<sup>26</sup> The APPG heard how pharmacists can become overburdened by the amount of information they are required to learn. As a critical part of the pathway for diagnosing patients, it is crucial pharmacists are given training and develop tools which take into consideration capacity pressures. The APPG also believes training courses should be available on a continuous basis to ensure pharmacists can access training alongside ongoing work commitments. A critical element of this is ensuring such CPD time is protected to ensure primary care professionals have the space to improve their knowledge.

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**“Appointments are only ten to fifteen minutes long, we are busy, often drowning in work just trying to get through the day.”**

Dr Anita Patel, Pershore Medical Practice

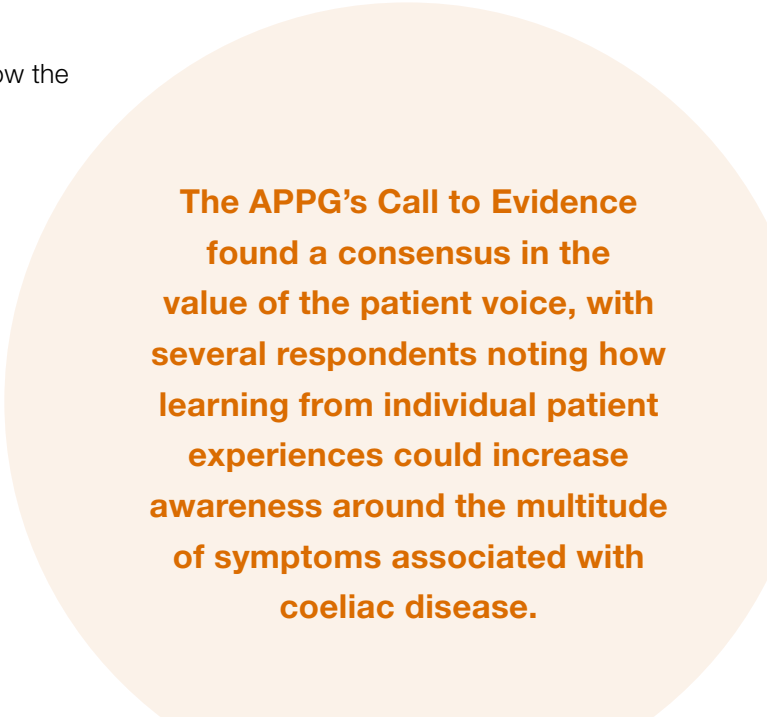
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**“Fitting in any education for practice staff is impossible with their current work commitments, they are often fighting the tide. One of the contrasts between working in the NHS and other companies outside of it, is what a completely different world it is outside of the NHS, in terms of having the time for education and learning materials. It seems protected time is a fantasy wish.”**

Dr Geraint Preest, Pencoed Medical Centre

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In the APPG's oral evidence sessions, the group heard how the British Medical Journal provides education and resources on coeliac disease through BMJ Learning, a website with resources tailored to a variety of HCPs such as nurses, pharmacists, generalist trainees and GPs.<sup>27</sup> However, the current resources available to HCPs require an individual to access training and education materials in their own time and of their own volition. Due to capacity pressures in the NHS, it is important HCPs are given protected time to access these training and educational materials.



**The APPG's Call to Evidence found a consensus in the value of the patient voice, with several respondents noting how learning from individual patient experiences could increase awareness around the multitude of symptoms associated with coeliac disease.**

## Chapter 3: Incentivisation and Case Finding

A common concern raised by GPs in the APPG's evidence sessions and within the Call to Evidence was the lack of financial incentive for practices to prioritise improving diagnosis of the condition. With coeliac disease diagnosis not reflected in the QOF or the commissioning for Quality and Innovation Framework, there is little financial incentive to apply low thresholds to testing for the condition. The QOF was created with the aim of financially rewarding general practices for the delivery of evidence-based standards of care.<sup>28</sup> We know, by looking at other condition areas such as diabetes, that QOF targets can positively impact health outcomes for patients and reduce pressures on other areas of the health service. QOF targets for coeliac disease would incentivise general practices to improve diagnosis rates, promoting the early detection and management of long-term conditions. This makes it an essential tool to support HCPs to deliver care for coeliac disease. Whilst the APPG recognises there is to be a consultation on the future of QOF, we believe any future incentives scheme should be assigned to coeliac disease to promote early diagnosis and improve a patient's quality of life.

Clinical audits are used to find out how healthcare is being delivered in line with guidance and standards. They allow patients and clinical communities to know which services are being delivered well and where there are gaps for improvement.<sup>29</sup>

The APPG has heard from HCPs regarding the barriers around carrying out local audits in primary care. Clinical audits can be a useful tool to achieve an earlier diagnosis as clinical awareness of the condition and symptoms can be improved. Audits can help to reduce the misdiagnosis of patients due to the large number of symptoms associated with coeliac disease that are synonymous with other conditions. Patterns in patients can be drawn out through audits, helping clinicians to spot the disease in patients sooner.

The APPG heard that more support needs to be provided to medical professionals carrying out clinical audits in primary care settings to incentivise GPs to carry out tests, without feeling bombarded by information.<sup>30</sup>

The APPG believes NHS England should increase awareness of the many benefits of using clinical audits. While they can be simple, due to ongoing capacity pressures in the NHS, it is often difficult for HCPs to set aside designated time to implement audits. The APPG has heard how NHS England launched the annual provider self-assessment (SA) in 2022, as the first multi-professional assessment process. The SA encourages learning providers to take ownership for assessing the quality of their learning environments and reinforces the importance of self-reporting.

The first national assessment focused on education and training. This tool promotes the use of self-assessment tools to support local quality assurance and improvement processes.<sup>31</sup> This allows HCPs to take ownership for assessments in their clinical area, putting in place mechanisms which can remove barriers to care delivery and promote long term improvements to the delivery of care for local populations. This can also reduce complacency with care delivery and ensure a model of care is created which naturally improves to meet the needs of patients. It is important HCPs are given more support to carry out audits in coeliac disease to improve awareness of the symptoms of the disease and support clinical interest in the area.<sup>32</sup>

For clinical audits to be carried out in primary care there needs to be engagement among GP practices across regional areas so assessments can be made on the standardisation of practice. This will allow comparisons to be made and HCPs can make assessments on the conclusions that are drawn from the audits. Additionally, statistics from the Call to Evidence found that over **90% of survey respondents said that they feel providing audit tool kits for trainee doctors and other HCPs would improve diagnosis rates and reduce misdiagnosis for patients.**

Given the capacity pressures on HCPs across the NHS, incentives should be offered to GPs to carry out local audits on patients with potentially undiagnosed coeliac disease.

## Chapter 4: Developing Diagnosis Pathways – No-Biopsy and the Role of Dietitians

The diagnostic pathway for coeliac disease and the rate of diagnosis<sup>30</sup> varies across the country and its efficacy is closely tied to local clinical engagement and leadership. During the APPG's oral evidence sessions, the group heard of areas of best practice that outline the ideal pathway for patients and could be used as examples to share across the UK. The group heard such clinical pathways should be whole system focused and patient-centred, with a focus on seeing the right HCP at the right time. They are dietetic-led with gastroenterologists seeing only those with the most complex needs, making use of digital tools to support self-care.<sup>34</sup>

### Case study: The Scottish Coeliac pathway

Characteristic of an effective clinical pathway for coeliac disease:

- Focuses on whole system working to increase awareness, ensure early detection and support, and provide care which supports self-management and lifelong living well.
- Shifts care into the community with dietetic-led, patient-centred and self-management focused care with lifelong community pharmacy support.
- Gastroenterology consultants only see people with the most complex coeliac disease, e.g., when the gluten-free diet has not improved symptoms and wellbeing.
- Makes use of digital platforms to better support people to manage their long-term condition at home.

One such example can be seen in the Scottish coeliac pathway developed by the Scottish Government. Whilst not yet in place in all parts of Scotland, the APPG heard of its successful implementation in Lothian.<sup>35</sup> One key element of this pathway is the role played by dietitians.

### The role of dietitians

Dietitians play a crucial role in the management of coeliac disease. In a standard pathway for diagnosis a patient receives a referral to a dietitian following a positive diagnosis, who helps provide advice and support around the management of a gluten free diet. They are recognised as being the experts in the field and key to the successful treatment of coeliac disease. A survey on patients with coeliac disease found that 65% of patients' first choice would be to see a dietitian, with 80% of those requesting a specialist dietitian.<sup>36</sup> The use of dietitians is cost effective, as it means patients experience fewer complications and will become less dependent on healthcare services. Dietetic-led clinics whereby the dietitian replaces the gastroenterologist and nurse-led coeliac clinics, have proven to be particularly effective. A recent study found that dietetic-led coeliac clinics helped to identify involuntary gluten ingestion, avoid repeat endoscopy and was associated with significantly improved adherence to the gluten free diet.<sup>37</sup>

**A survey of patients with coeliac disease found that 65% of patients' first choice would be to see a dietitian, with 80% of those requesting a specialist dietitian.<sup>36</sup>**

The APPG also heard evidence in favour of further utilisation of dietitians within the diagnosis pathway. In Lothian in Scotland, the patient has an initial appointment with a dietitian who assesses the patient and talks them through the referral pathway.<sup>38</sup> Dietitians can provide patients with a more tailored intervention that meets their individual needs and maintains overarching coordination over the patient's diagnosis journey. Approaching diagnosis in this manner aims to ensure the patient has a better understanding of their condition and the rationale behind the diagnosis. This approach is also reflected in the Western Health and Social Care Trust (WHSCT), Northern Ireland where qualified dietitians play a central role in the diagnosis of the condition.<sup>39</sup>

However, despite positive examples in parts of the UK, dietetic-led services are underutilised across the country. A recent survey completed by 158 dietetic departments in England that provide dietetic gastroenterology services identified that specialist dietetic coeliac disease clinics were not provided in 49% of these services.<sup>40</sup> The APPG heard that Trusts and Health Boards are dependent on expert dietitians to lead the development and implementation of services which creates variation in how services are set up across the country. However, dietetic-led services in fact save money, with savings and benefits to patients' quality of life shown in the long-term.<sup>41</sup> To set up a dietetic-led service requires local clinicians to champion the condition and understand the long-term value gains of running a service in this way. However, there is a shortage of dietitians in the NHS, which is exacerbated by a lack of dietitians with an expertise in coeliac disease. The APPG would like to see dietitians better incentivised to become experts in the diagnosis and management of coeliac disease.

**“Areas where there is best practice, are the areas where there are individual champions [...] In our area [Lothian, Edinburgh], we are lucky enough to have a dietetic-led service. For me, dietitians are the way forward for cost-effective, expert management, with an individual go to medic.”**

Dr Peter Gillett, Royal Hospital for Children and Young People, Edinburgh.

Creating a dietetic-led service will help reduce the strain on secondary care services and will improve the patient experience of diagnosis. Patients have reported feeling lost in the system after they are discharged back into primary care services, with concerns raised over the loss of follow-up appointments for patients following a diagnosis.<sup>42</sup> In 2018, Coeliac UK's Post Diagnosis Care Survey found that 60% of respondents were not offered an annual review to monitor their condition for coeliac disease.<sup>43</sup> The APPG believes in the importance of an established relationship between gastroenterologists and dietitians to ensure patients are fully supported following a diagnosis.

### Endoscopy waiting lists and the role of no-biopsy strategy

Delays in secondary care settings also have an impact on patients with coeliac disease as they are unable to access appointments and endoscopy procedures, which are often used to confirm a diagnosis in secondary care. Over 50% of those who answered the Call to Evidence thought the length of endoscopy waiting times had an impact on coeliac disease diagnosis, with many noting the long-term health implications of delayed diagnosis.<sup>44</sup> The growing demand for endoscopy services across the NHS has caused a strain in the availability of the procedure. In February 2020, 9.1%<sup>45</sup> of patients were waiting 6 weeks or more for a gastroscopy, this figure has risen to 35.1%<sup>46</sup> in April 2023.

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The backlog in access to care is seen across the United Kingdom, with the APPG hearing anecdotal evidence that waiting times in Scotland can depend on the patient's ability to travel longer distances to receive treatment. Patients who can travel for treatment are often waiting six weeks for treatment, whereas for those unable to travel, this increases substantially to up to two years. By prioritising coeliac patients, the service can fast track a cohort with a clearly defined treatment plan and clear capacity for complex cases.<sup>47</sup>

Given the significant waits for endoscopy, a no biopsy strategy offers the opportunity for many of those with suspected coeliac disease to get a quicker, less invasive diagnosis. Whilst the majority of patients would still require a biopsy, a no-biopsy approach could be applied to those adult patients who are under 55 years of age, with suspected coeliac disease and an IgA tTG antibody level 10x higher than normal.<sup>48</sup> The APPG heard estimates that this could apply to around 20% of adults awaiting a diagnosis.<sup>49</sup>

### What is a no-biopsy strategy?

A no-biopsy strategy for coeliac disease is an innovative diagnostic approach aimed at expediting and simplifying the process of diagnosing the condition. Traditionally, the diagnosis of coeliac disease has required an invasive procedure known as an endoscopy, which involves taking a biopsy of the small intestine to confirm the presence of characteristic damage caused by gluten consumption. However, the no-biopsy strategy seeks to minimise the necessity for biopsies and their associated challenges.



In a no-biopsy pathway, a patient suspected of having coeliac disease would first undergo blood tests to measure specific markers, such as IgA tTG antibody levels. If these blood tests reveal significantly elevated levels, indicating a strong likelihood of coeliac disease, the next step involves consulting a gastroenterologist. This specialist evaluates the patient's clinical history, symptoms, and blood test results to determine whether an endoscopy and biopsy are required for confirmation.

While most individuals would still need a biopsy for definitive diagnosis, the no-biopsy approach can be applied selectively to certain cases. Typically, it is considered for adult patients under the age of 55, whose symptoms and blood test results strongly suggest coeliac disease. This approach aims to minimise unnecessary invasive procedures, reduce patient discomfort, and expedite the diagnostic process.

The no-biopsy strategy represents a significant advancement in coeliac disease diagnosis, offering a more streamlined and patient-friendly approach that relies on a combination of clinical evaluation, serology (blood tests), and the expertise of HCPs to make accurate diagnostic decisions. Already in place for children, this approach has the potential to improve the efficiency of adult diagnosis while maintaining the accuracy and reliability necessary for appropriate patient care and reducing pressure on overburdened endoscopy waiting lists.

### Serology testing

When diagnosing a patient with coeliac disease, a serology test - a blood test<sup>50</sup> - is used to identify antibodies that are produced by the body in response to eating gluten. People should be offered serological testing when they present with symptoms of undiagnosed coeliac disease. Serology has a critical role in the diagnosis pathway, either to detect possible coeliac disease or to confirm a diagnosis of the condition.<sup>51</sup>

In oral evidence sessions, the APPG heard from clinicians about the complex landscape in the standardisation of serology testing. There is a need for the standardisation of testing in the pathway, and it is important that this comes with knowledge of the IgA tTGA levels from local labs to ensure there is agreement between labs and HCPs on what is a 'safe' IgA tTGA level. The APPG believes local audits should be carried out to improve the understanding of the performance of serology test kits at a local level. The APPG believes that clinicians should have a low threshold for testing for coeliac disease in recognition of the varied symptoms and associated risk factors.

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**“These are rapid tests, and we get results quickly, facilitated by local labs doing them. Centralisation may be detrimental and delay the time, to 2-3 weeks rather than 2 days. The rapidity of the test is one of its advantages.”**

Dr Helen Gillet, St John's Hospital, Livingston

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## Case Study: Standardised serology guidance for coeliac disease in Wales

Dr Ieuan Davies (Consultant Paediatric Gastroenterologist) and Dr Richard Cousins (Consultant Clinical Immunologist) from Cardiff & Vale University Health Board worked together to develop a simple prompt to support better diagnosis of coeliac disease. By developing a standard message to accompany all paediatric coeliac serology tests, they were able to signpost the requester to the appropriate next steps.

This change in reporting will help to avoid common errors in the diagnosis pathway, support other HCPs to meet the NICE quality standards and to limit disruption and harm to children. Discussions are underway to update the reporting for adult coeliac disease blood tests as well.

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When an HCP requests a test on a child under 16, the following messages will be presented on the blood results to the requester:

### **Abnormal (IgA tTG or IgG tTG) result:**

This child may have coeliac disease. Please recommend they must remain on a normal gluten containing diet until they are assessed by an expert and all diagnostic tests are complete. Please make an urgent paediatric outpatient referral stating, "possible coeliac disease".

### **Normal (IgA tTG) result:**

To exclude coeliac disease with confidence this child must have a normal IgA level and must have been eating a normal gluten containing diet for at least 6-8 weeks prior to this blood test. If you still have concern, please make a paediatric outpatient referral for expert advice.

## National Diagnostic Pathway for lower gastrointestinal symptoms in primary care

Whilst the symptoms of coeliac disease can be varied, it is often associated with lower gastrointestinal (GI) symptoms. Such symptoms are common within the general population across all ages and so it can be challenging for patients and HCPs to identify the correct route for diagnosis at the right time. In recognition of this challenge, several partners have come together from within the health service and third sector to develop a single diagnostic pathway for lower gastrointestinal symptoms. A recommended pathway for screening and testing of patients who present with lower GI symptoms in primary care in the UK, to aid the diagnosis of relevant lower GI conditions (including cancer) will support a uniform approach across ICSs Integrated Care Systems (ICSs) in England.

- Appropriate criteria for paediatric and adult patients who should be investigated (including age, symptom duration, current medicine use, and dietary considerations) and the order of tests to be carried out.
- A toolkit to improve patient understanding and experience of diagnosis in primary and community care settings.

## Chapter 5: Public Awareness of Coeliac Disease and its Symptoms

The APPG identified a lack of public awareness of coeliac disease and its symptoms as one of the most significant barriers to diagnosis of the condition. A study by YouGov on behalf of Coeliac UK, found that nearly 1 in 5 (19%) did not know or recognise any of the listed symptoms associated with coeliac disease. There was also a statistically significant difference in the lack of awareness of coeliac disease between the social grades (ABC1-middle=23%, C2DE-working =31%). Only 12% were aware that mouth ulcers can be associated with undiagnosed coeliac disease and only 7% aware that subfertility and recurrent miscarriages can also be associated with coeliac disease.<sup>52</sup> Furthermore, during the APPG's oral evidence session, experts raised concerns over a lack of awareness in different ethnic groups. Research by the University of Nottingham found a disparity in the rates of diagnosis amongst different ethnic groups (e.g. the rate of diagnosis of coeliac disease in the Black British population is only a fifth of that for White British).<sup>53</sup>

The APPG notes and welcomes recent public awareness campaigns such as Coeliac UK's 'Is it Coeliac Disease?' and most recently '**Coeliac disease is different for everyone**' campaign. The month of Awareness Week saw more than a four-fold increase (May n=13,349 vs April n=3,023) in people completing Coeliac UK's online symptom checker tool compared to the previous month. More than 99% of all completions were recommended to have a test or be considered for testing. However, there is a limit to the reach and impact a single organisation can achieve and the APPG would like to see NHS England and the Government working together with third sector organisations, such as Coeliac UK to improve awareness of coeliac disease among the population. The APPG believes the Government and NHS England should seek to improve its understanding of the barriers to awareness experienced by different ethnic groups. To remove these barriers, the Government and NHS England should engage with community groups to use tailored methods and tools to improve awareness of coeliac disease.





## Recommendations

### Improve understanding of coeliac disease and its symptoms amongst HCPs

NHS England and Government should:

- Support the dissemination of key messaging to GPs and pharmacists on coeliac disease and the need for early diagnosis.
- Support the development of a coeliac disease training programme for primary care physicians and other Allied Health Professionals (AHPs) so that they can better understand the complex nature and diverse manifestations of coeliac disease.
- Encourage GPs to approach coeliac disease with a low threshold for testing and recognise the varied symptoms associated with the condition.
- Provide pharmacists with tailored education and support tools to assist in the diagnosis of coeliac disease in primary care.
  - As a crucial part of the system, the awareness of coeliac disease in pharmacies needs to be improved. Tailored educational materials should be developed to meet the needs of pharmacists and support their ongoing work commitments.

### Incentivising case finding

NHS England and Government should:

- Improve incentivisation in primary care to follow existing NICE guidelines<sup>10</sup> on coeliac disease.
  - Medical professionals need to be given more support to follow guidance which outlines the pathway for diagnosing coeliac disease in primary care settings.
  - QOF and Quality and Innovation Frameworks should reflect the benefits of early diagnosis of coeliac disease and reward best practice.
- Implement support mechanisms to assist HCPs in primary care to carry out clinical audits.
  - It is important HCPs are given allocated time to carry out clinical audits to further the clinical understanding of coeliac disease and support the sharing of best practice across the country.

### Developing unified clinical pathways (No-biopsy and dietetic-led services)

NHS England and Government should:

- Support the adoption of dietetic-led services across the country.
  - This will allow patients to be referred to a dietitian who can provide specialist knowledge to empower patients to manage their condition as they move along the pathway to receive a diagnosis, and where appropriate adopt a no-biopsy route to diagnosis.
- Commit to adoption of a unified diagnostic pathway for lower GI symptoms in primary care.
- Work with professional bodies such as the British Dietetic Association and British Society of Gastroenterology to promote the relationship between dietitians and gastroenterologists to better support the long-term management of patients with coeliac disease.
- Develop coeliac endoscopy lists, prioritising those with suspected coeliac disease so that these patients' cases can be resolved quicker, therefore relieving pressure on the system.
- Support further research into the efficacy of dietetic-led clinics and support expansion of their use in England.

## Raising awareness amongst the general public

NHS England and the Government should:

- Develop a public health campaign to raise awareness of coeliac disease and its symptoms.
  - This could be done through educational materials such as posters and leaflets in hospitality venues, GP practices and pharmacies.
- Link up with HCP champions and Coeliac UK to support existing public awareness campaigns such as Coeliac UK's Awareness Week.



## Conclusion

In conclusion, the timely and accurate diagnosis of coeliac disease in primary care is of utmost importance to improve the lives of affected individuals and reduce the potential for long-term complications. The complex pathway to diagnosis, can lead to misdiagnosis and delays in treatment. Therefore, it is essential to equip primary care professionals, including GPs, nurses and pharmacists with the necessary knowledge and resources to identify coeliac disease promptly.

Incentivising primary care professionals is crucial to empowering them to make timely diagnoses. Professional development and training opportunities should be readily available, and HCPs should be provided with dedicated time for awareness training. To identify barriers to diagnosis and improve patient outcomes, clinical audits should be incentivised to promote increased awareness and timely referrals for blood tests. Coeliac disease diagnosis should be reflected in the QOF or the commissioning for Quality and Innovation Framework, there is little financial incentive to apply low thresholds to testing for the condition.

The diagnostic pathway from primary to secondary care can be improved through standardised processes and dietitian-led service, mandated across the country to enhance patient support, and reduce strain on secondary care services. The long waiting lists for endoscopies must be addressed. It is essential to expand the use of the no-biopsy strategy in adults, where appropriate, to speed up the diagnosis pathway and improve patient outcomes.

Further, patient awareness of coeliac disease is crucial, and efforts should be made to educate the public on the various symptoms that may present themselves. This can empower patients to advocate for themselves and prompt early testing if they suspect coeliac disease.

A multi-faceted approach is needed to address the challenges and improve the diagnosis of coeliac disease in primary care. By enhancing awareness, providing tailored education, incentivising professional development, and implementing the no-biopsy strategy where suitable, we can reduce the time to diagnosis and ensure better care for individuals living with coeliac disease.



## HCP CASE STUDIES:

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### Case study – HCP Education (Dr Geraint Preest, GP & Primary Care Editor for BMJ OnExamination)

Dr Geraint Preest spoke of the BMJ's OnExamination tool that provides practice revision questions for clinicians sitting their membership exams for the Royal College of GPs.

Dr Preest explained that, as a GP with a particular interest in coeliac disease himself, he ensures that the tool is well populated with questions on coeliac disease and particularly known points of error and areas where there is existing lack of knowledge. As part of the revision process, GPs are given clinical scenarios and asked for the action they would take. Dr Preest explained how useful it was to understand the wrong answers in order to better understand GP behaviour to support and educate them to take the correct action in the future.

By addressing deficiencies in knowledge, GPs can make better use of resources and testing. Stats from answers show that there is significant misunderstanding around coeliac disease. It is often seen as a solely gastroenterological condition, there is limited understanding of comorbidities and misapprehension around testing that could have an impact on the patient's chance of successful diagnosis.

Effective training of GPs is a win-win, as not only do you improve knowledge of those taking part you can also learn a lot about deficiencies in knowledge, to better tailor training resources going forward.

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### Case study - Audit Tool Kits (Dr Leo Penrose - F2 Junior Doctor)

Dr Penrose spoke to the APPG about his development of an audit toolkit for use in secondary care. Junior Doctors are required to carry out at least one quality improvement activity each year as part of their foundation phase. Dr Penrose carried out an audit focused on the NICE guideline for coeliac disease and the recommendation to test patients for coeliac disease if they have unexplained deficiency in iron, B12 or folate. The serological test can be carried out on an existing sample so does not require additional blood to be taken.

Out of 400 patients seen in A&E, 113 (roughly 1 in 4) were deficient in Iron, B12 or folate. Of these 113, only 11 had been tested for coeliac disease via IgA tTG antibodies. This suggests a significant undertesting of the cohort.

Dr Penrose suggests this could be addressed by HCP education (use of educational posters), ongoing audits and monitoring. Every 3 months there is a rotation of doctors who could be encouraged to carry out such an audit and measure improvement from previous results. This currently takes place for a number of other conditions. For example, in the case of anti-coagulation medication, staff are expected to meet near 100% adherence to the recommendations. There is an opportunity to apply this to coeliac disease, however it requires the case to be made to senior supervising doctors regarding its benefits.

As such it is critical that doctors are made aware of the need for early diagnosis of coeliac disease and the implications of failing to do so.

Junior doctors are afforded two hours of self-development time (SDT) time each week, as recommended by Health Education England. This would provide a prime opportunity to undertake such audits.

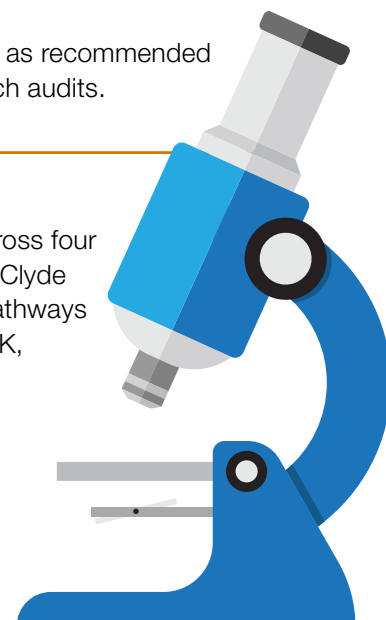
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### Case study - Scotland and the coeliac disease pathway

In 2018, a new national evidence-based pathway for coeliac disease was launched across four health boards in Scotland (NHS Lothian, NHS Lanarkshire, NHS Greater Glasgow and Clyde and NHS Tayside). It was funded by the Scottish Government's Modernising Patient Pathways Programme and co-produced in partnership with key stakeholders including Coeliac UK, people living with coeliac disease, and clinicians.

The dietetic-led pathway delivers early diagnosis, early intervention, and support, so people can self-manage their condition with monitoring via community pharmacy.

The pathway was seen as a success however to date adoption by health boards has been patchy and inconsistent. The charity believes implementation of the pathway on a once for Scotland basis should be a priority for the Scottish Government.



## PATIENT CASE STUDIES:

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### Case study – Ben Cirne

At the age of 16, Ben noticed he always felt completely exhausted but put it down to his busy life as a student athlete, which revolved around playing football, basketball, and rugby.

“I’d been very active and sporty throughout my whole life. I’d be the butt of the jokes because I’d always be napping. On a 20 minute car journey I’d need a sleep and at first I didn’t think too much of it because I was always busy doing something active.”

As he got older Ben assumed work stress was the cause of his continued tiredness but it was becoming a dad that made him realise that something was not quite right:

“I had my little one three years ago and everyone says you’re tired as a parent but mine was just different, it wasn’t right. I had stomach cramps and pains after every meal and the symptoms just got stronger. I realised it was nearly 10 years I’d been feeling this way and I wanted to get it investigated.”

The pandemic hit just as Ben was starting investigations, so it was only in September 2022 that he finally received a diagnosis following a positive blood test and endoscopy.

“I had to ask the doctor: ‘What is coeliac disease?’ I’d never even heard of it!”

Since diagnosis, Ben has been strictly gluten free and his symptoms have improved significantly.

“I feel 100 times better. The tiredness and fatigue has pretty much gone now, I’m back to being fresh – as much as a parent to a 3 month old and a 3 year old can be!”

“People often ask me what I’m eating at work and that gives me the opportunity to talk to them about my experience - I’ve grown to want people to ask me because I didn’t put two and two together. When they hear the statistics about how many people are undiagnosed, it really gets them thinking.”

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### Case study - Nicola Dixon (Frankie’s mum)

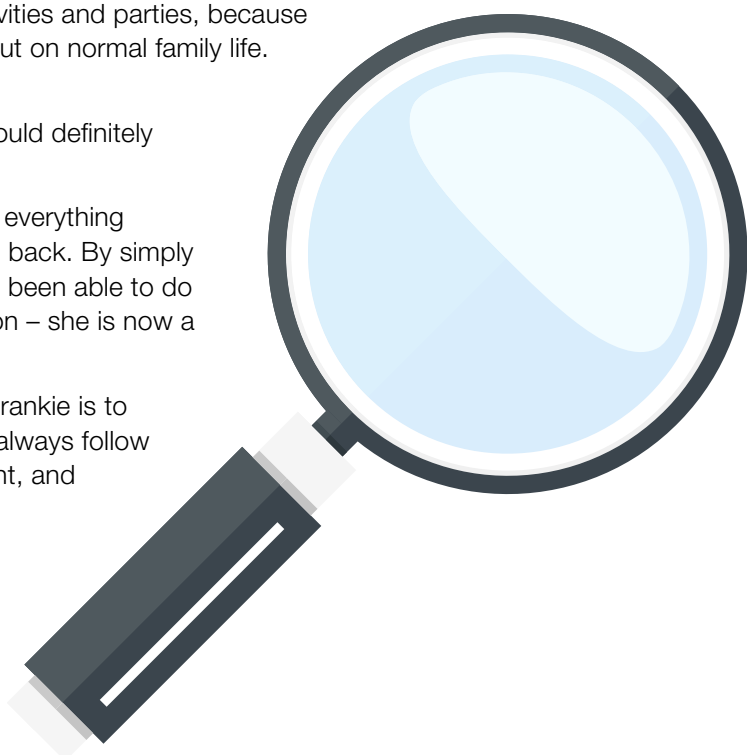
“We first noticed symptoms when Frankie was around 18 months old. Of course, being so young she couldn’t tell us what the matter was. But we noticed that she was constantly vomiting and didn’t want to move from the sofa. We knew it wasn’t right.

Some days I used to hold her, and she would be crying and I just felt so helpless. Frankie missed out on so much, including nursery activities and parties, because she was so weak and unwell. Most of all she missed out on normal family life. She couldn’t even enjoy a family film.

Looking back, it was tough to get a diagnosis, but I would definitely recommend anyone to keep on pushing for answers.

When we finally found out Frankie had coeliac disease everything completely changed. Within two days we had our lives back. By simply cutting out gluten we could do all the things we hadn’t been able to do for so long. Frankie is now a completely different person – she is now a vibrant, happy, and energetic little girl.

My advice to anyone with a child with symptoms like Frankie is to demand a test. Don’t let your child suffer and always, always follow a parent’s instinct. You know when something isn’t right, and eventually you’ll get the answers you need.”



# Appendix

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## Oral Evidence Sessions

The APPG on Coeliac Disease held 5 oral evidence sessions in April and May 2023.

### Session 1

Dr Anita Patel, Pershore Medical Practice  
Dr Geraint Preest, Pencoed Medical Centre  
Dr Gerry Robins, York & Scarborough Teaching Hospitals NHS Foundation Trust  
Rosie Taylor, Pharmaceutical Services Negotiating Committee

### Session 2

Dr Peter Gillett, Royal Hospital for Children and Young People, Edinburgh  
Dr Helen Gillett, St John's Hospital, Livingston  
Dr Ieuan Davies, University Hospital of Wales

### Sessions 3

Dr Laila Tata, University of Nottingham  
Ben Cirne, Patient with lived experience  
Nick Trott, Hallamshire Hospital Sheffield  
Heidi Urwin, Coeliac UK

### Session 4

Joanne Casey, Western Health and Social Care Trust, Northern Ireland  
Dr Leo Penrose, John Radcliffe Hospital, Oxford University Hospitals, NHS Foundation Trust  
Joy Whelan, Western Health and Social Care Trust, Northern Ireland

### Session 5

Dr Charlie Andrews, Clevedon, North Somerset

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## Call for Evidence

The APPG on Coeliac Disease opened its Call for Evidence in March 2023 and closed the consultation in July 2023. The APPG received 120 responses to the request for evidence.

1. RCGP. (2021) "Practical training - Coeliac disease, the patient and the community experience" *Royal College of General Practitioners Online Webinar*
2. APPG on Coeliac Disease. (2023) "Oral Evidence Session" *All-Party Parliamentary Group on Coeliac Disease*
3. CPPE. (2014) "Coeliac disease - new floor on the Learning pharmacy. com" *Centre for Pharmacy Postgraduate Education* Available at: <https://www.cppe.ac.uk/news/a/372/thelearningpharmacy.com-new-floor>
4. NHS England. (2023) "Commissioning for Quality and Innovation (CQUIN): 2023/24" *NHS England* Available at: <https://www.england.nhs.uk/wp-content/uploads/2022/12/Commissioning-for-Quality-and-Innovation-CQUIN-2023-24-guidance-version-1.2-1.pdf>
5. NHS England. (2023) "Pharmacy Quality Scheme" *NHS England* Available at: <https://www.england.nhs.uk/wp-content/uploads/2021/09/PRN00176-pharmacy-quality-scheme-guidance-23-24-v2.pdf>
6. BSG. (2020) "BSG Interim Guidance: COVID-19 specific non-biopsy protocol for those with suspected coeliac disease" *British Society of Gastroenterology*
7. Jeanes Y et al. (2023) "Coeliac disease: In person appointments and annual reviews remain important for a subset of patients" *BSG Annual Conference*
8. APPG on Coeliac Disease. (2023) "Oral Evidence Session" *All-Party Parliamentary Group on Coeliac Disease*
9. Coeliac UK. (2023) "YouGov Survey Data Analysis – Awareness Week 2023 Campaign" *Coeliac UK*
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17. BSG. (2022) "BSG Interim Guidance: COVID-19 specific non-biopsy protocol for those with suspected coeliac disease" *British Society of Gastroenterology* Available at:
18. APPG on Coeliac Disease. (2023) "Oral Evidence Session" *APPG on Coeliac Disease*
19. Coeliac UK. (2022) "Improving diagnosis rates for those living with coeliac disease" *Coeliac UK*
20. RCGP. (2021) "Practical training - Coeliac disease, the patient and the community experience" *Royal College of General Practitioners Online Webinar*
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