

## Qualitative interviews to explore patient preference for an intervention to promote gluten-free dietary adherence

H Muhammad<sup>1</sup>, S. Reeves<sup>1</sup>, S Ishaq<sup>2</sup>, J Mayberry<sup>3</sup> YM Jeanes<sup>1</sup>

<sup>1</sup>Health Sciences Research Centre, University of Roehampton, London. <sup>2</sup>Gastroenterology, Dudley Group of Hospitals, <sup>3</sup>Gastroenterology, University Hospitals of Leicester

### INTRODUCTION

- A gluten free diet, in people with coeliac disease, leads to symptomatic improvement, histological remission of villous atrophy, improvements in quality of life and reduction in the risk of osteoporosis and gastrointestinal malignancies.
- However, a gluten free diet is difficult to follow and many patients refer to social and practical issues. Dietary adherence to the gluten free diet in coeliac disease has been reported to range from 36% to 96% (Muhammad *et al* 2019).
- Factors that influence adherence include sociodemographic, age of diagnosis, practical difficulties associated with the gluten free diet and membership of advocacy groups (Muhammad *et al* 2017). An intervention to promote dietary adherence should be informed by patients with coeliac disease to help ensure relevance and acceptability.

**STUDY AIM:** Explore the preferences, of adults with coeliac disease, for a healthcare professional led intervention to improve gluten free dietary adherence.

### METHODS

- Participants were recruited from the coeliac disease database held within the University Hospitals of Leicester's pathology department.
- A postal survey included the coeliac disease adherence test (CDAT) questionnaire (Leffler *et al* 2009) with available support in 7 ethnic languages. Pilot interviews were undertaken (n=13) to inform the qualitative telephone interviews.
- Closure of the interviews was based on data saturation, by repeatedly comparing data across participants, which occurred when no new information was obtained from the interviews. Thematic analysis identified key themes. Data was analysed in NVIVO8 version 11.
- Patients were asked to compare proposed intervention cost, usefulness, behaviour change & knowledge potential and cover effectiveness of different techniques via a Likert scale.
- Ethical approval was granted through the procedures of the University of Roehampton and the NHS Research and Ethics Committee (LCS 15/130 and 15/YH/0289).
- Values presented are the number of participants providing that view point.

### RESULTS

- Thirty seven patients with histology proved diagnosis of coeliac disease completed the telephone interviews with H Muhammad (up to 30 minutes each).
- Twenty eight Caucasians and nine South Asians (29 females and 8 males).
- Thirty participants were classified as not adhering to the GF diet, >13 CDAT score (Leffler *et al*, 2009). All non-adherent participants expressed their desire to improve their GF dietary adherence.

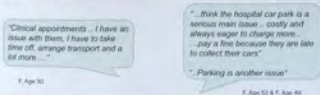
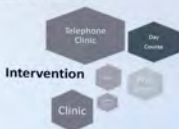


Figure 1. Quotes from theme 1 to 1 clinic



#### One to one clinic appointment

- Participants considered the clinic appt. with dietician or/and gastroenterologist to be full of information (33), however there were negative comments around the practicalities of attending (figure 1); Parking was considered expensive (36) and difficult to get (20).
- Usefulness was rated 6 out 10, and cost to patient 5 out of 10.

#### Telephone clinic

- Telephone clinic was considered easy (33), flexible (29) cost effective (28) and convenient (19) for the patients. Concern about the lack of face to face (4) were raised.
- Usefulness was rated 6 out 10, and cost to patient 9 out of 10.

#### Group education day

- A study day was valued by mainly Caucasians (18), with group support (10) cited as a key reason. However, the same negatives as attending a clinic were reported: travel costs, parking and the time required to attend.
- Usefulness was rated 8 out 10, but cost to patient 2 out of 10.

#### Online intervention

- Participants indicated they would want to interact with the healthcare professional(s) and to be able to ask questions.
- Usefulness was rated 3 out 10, with cost rated 8 out of 10

### CONCLUSION

- This study has given a unique view of a multi-ethnic population to inform interventions aimed at increasing adherence to a gluten-free diet. Patients highlighted the usefulness of interaction with the healthcare professional (being able to ask questions), privacy, low cost and convenience to them.
- Whilst acknowledging its limitations, this study has strengthened the viewpoint that patients are crucial in all aspects of the treatment and management of chronic diseases, including the design of interventions and service development.
- An intervention study is needed to establish whether a telephone clinic, which offers patient centered consultation, can increase gluten-free dietary adherence.

#### REFERENCES

- Muhammad H, Reeves S, and Jeanes YM (2019) Identifying and improving adherence to the gluten-free diet in people with coeliac disease. *Proceedings of the Nutrition Society Epistix* doi.org/10.1017/S095026881900227X.
- Muhammad H *et al* (2017) Adherence to a Gluten Free Diet is Associated with Receiving Gluten Free Foods on Prescription and Understanding Food Labeling. *Nutrients* Jul 6,9(7).
- Leffler, Dierme, Edwards George, Jamna, Maggan, Cook, Schuppman, & Kelly (2009) A simple validated gluten-free diet adherence survey for adults with coeliac disease. *Clinical Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological Association*. 7(10): 520-6.



*K Powell, L Coxden, Specialist Gastroenterology Dietitians,  
C Best, Nutrition Nurse Specialist, E Kyriazidou, Dietetic Assistant*

## INTRODUCTION

NICE (2016) recommends patients with coeliac disease are offered an annual review to assess adherence with a gluten-free diet, review symptoms and provide advice about coeliac disease/diet<sup>1</sup>. The British Society of Gastroenterology (2014) recommends patients with coeliac disease should be reviewed by a dietitian and/or a clinician with an interest/expertise in coeliac disease<sup>11</sup>.

The coeliac team at Hampshire Hospitals Foundation Trust comprises of two gastrointestinal dietitians and one nutrition nurse specialist and offer patients with coeliac disease within their CCG an annual appointment.

Prior to their appointment patient bloods are checked for tTG antibodies, folate, vitamin B12, ferritin, vitamin D, haemoglobin and liver function.

As standard, during an appointment adherence to a gluten-free diet, symptoms, weight and dietary intake are discussed.

The aim of this short study was to identify what additional advice the team was providing to patients at their annual coeliac review.

## METHOD

A proforma was used in the clinic to collect information. This information was then inputted onto a spreadsheet and analysed.

## RESULTS

The study took place between July-October 2018. During this period 139 coeliac reviews were undertaken. 37% of patients required advice regarding vitamin D supplementation, 35% required advice regarding increasing their calcium intake and 25% of patients required advice regarding a low ferritin level (see figure 1). Advice was also provided to patients regarding their folate (4%) and vitamin B12 (3%) levels and regarding gastrointestinal symptoms including bloating (7%), constipation (5%) and diarrhoea (4%). Concerns were raised by individual patients that would not typically be discussed at a coeliac review, including advice regarding a cholesterol reducing diet, a low sulphite diet and introducing fibre after surgery (see table 1).

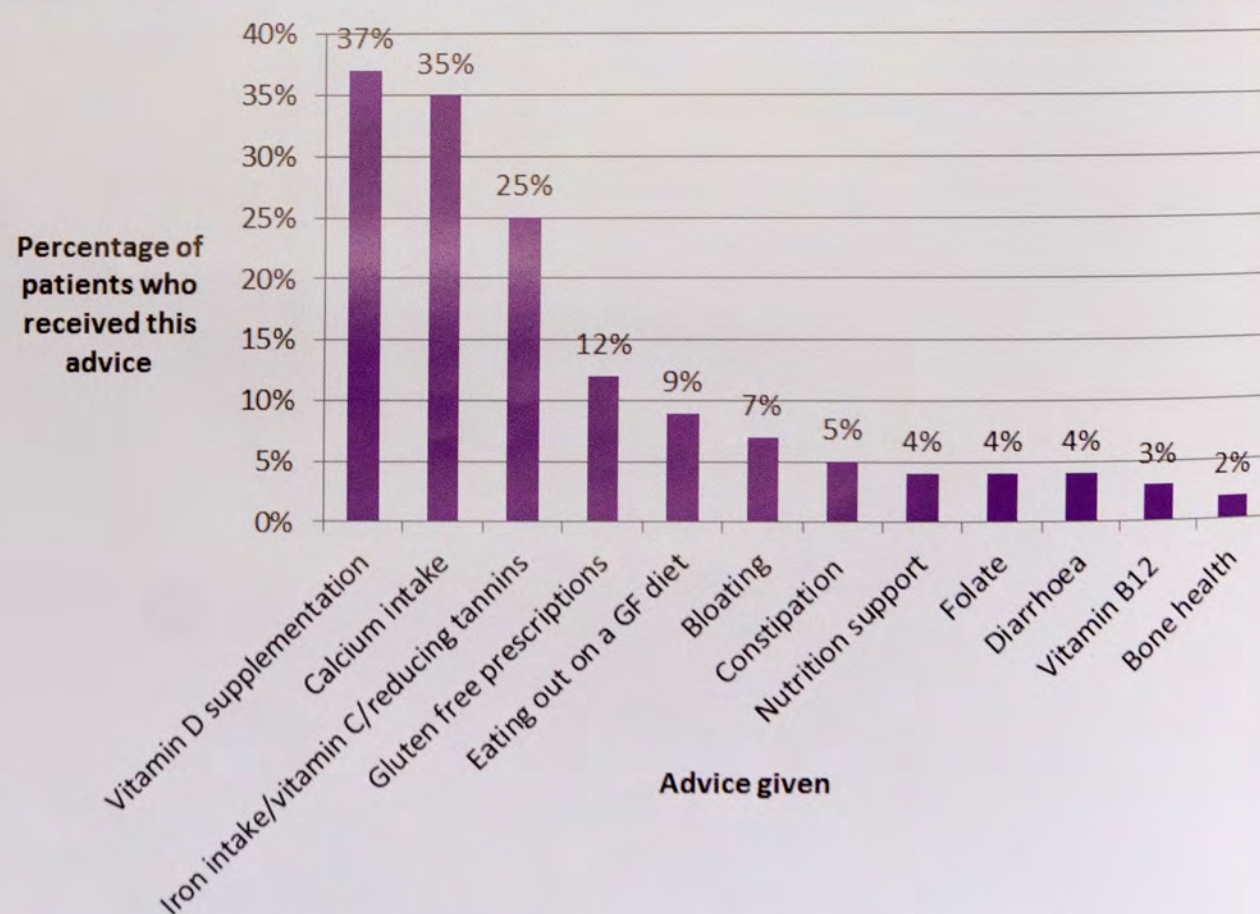


Figure 1: Advice provided in addition to gluten free diet advice

Table 1: Additional advice requested by patients

Advice
• Healthy eating
• Low sulphite diet
• Cholesterol reducing diet
• Introducing fibre after surgery
• Dietary advice for thyroxine
• Low FODMAP diet
• Urgency of stools
• Raised ALT

## DISCUSSION

The results of the study demonstrate that a coeliac review does not only discuss adherence to a gluten free diet, as patients have additional nutritional concerns and gastrointestinal symptoms that need to be addressed. In addition the study demonstrates that non-coeliac related concerns can be raised and therefore justifies the rationale for a specialist dietetic team to provide the annual reviews.

1. NICE (2016) Coeliac Disease Quality standard [QS134] <https://www.nice.org.uk/guidance/qs134/chapter/quality-statement-5-annual-review>  
2. Ludvigsson et al (2014) Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology <https://www.bsg.org.uk/resource/bsg-guidelines-on-the-diagnosis-and-management-of-adult-coeliac-disease.html>



L Coxden and K Powell, Specialist Gastroenterology Dietitians, Hampshire Hospitals Foundation Trust

## INTRODUCTION

Bone health is an important consideration in the medical management of coeliac disease but vitamin D testing is not routinely recommended. Patients with coeliac disease are more likely to have fragility fractures<sup>i</sup>, are recommended to have a high calcium intake compared to the general population<sup>ii</sup> and may have persisting vitamin D deficiency despite a gluten free diet<sup>iii</sup>. Nationally, vitamin D deficiency (<25nmol/L) is estimated at 30-40% during winter<sup>iv</sup>. Clinical guidelines state levels of <30nmol/L should be treated<sup>v</sup>.

The aim of this study was to assess the prevalence of vitamin D deficiency in coeliac patients attending their annual review during the winter 2017/18 and establish if routine monitoring of vitamin D is justified in this cohort of patients.

## METHOD

Patients who were booked into annual review clinics between January and March had their demographic information, tTG level and vitamin D level reviewed retrospectively. Deficiency was defined as levels <30nmol and insufficiency as 30-50nmol as per the National Institute for Clinical Excellence<sup>v</sup>.

## RESULTS

During the period studied, 120 patients were booked into a coeliac annual review clinic at Hampshire Hospitals Foundation Trust. The mean age of people attending was 48 years. 92 (77%) of patients were female and 28 (33%) were male. 99 patients (82.5%) identified themselves as white British, 8 (6.7%) as any other ethnicity, 2 (1.6%) as any other white ethnicity and 2 (1.6%) Indian. We were unable to gather ethnicity information for 9 (7.5%) of the cohort. Tissue Transglutaminase was negative for 97 of 120 patients (Fig 1). 106 of the total 120 patients had their vitamin D levels tested. Of the 106 patients who had their vitamin D levels tested, 46 patients had sufficient levels (>50nmol/L), 25 patients had insufficient levels (30-50nmol/L) and 35 patients were deficient (<30nmol/L) (Fig 2).

Figure 1:

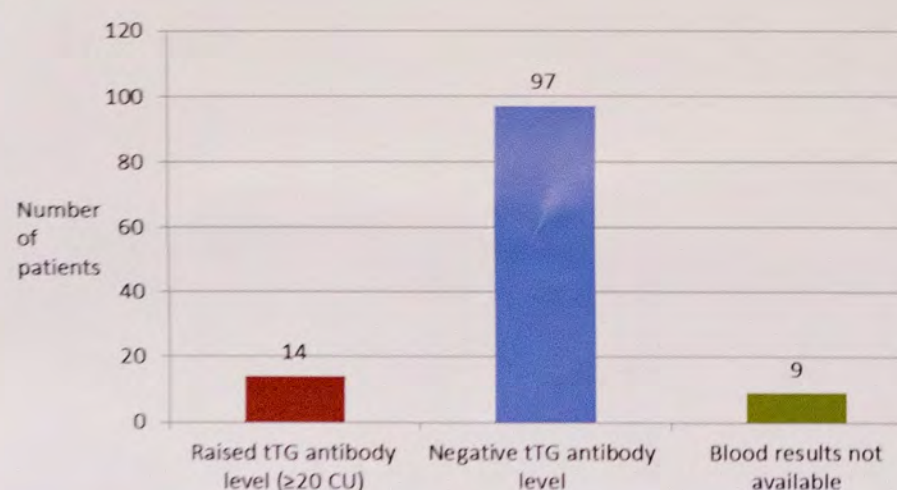
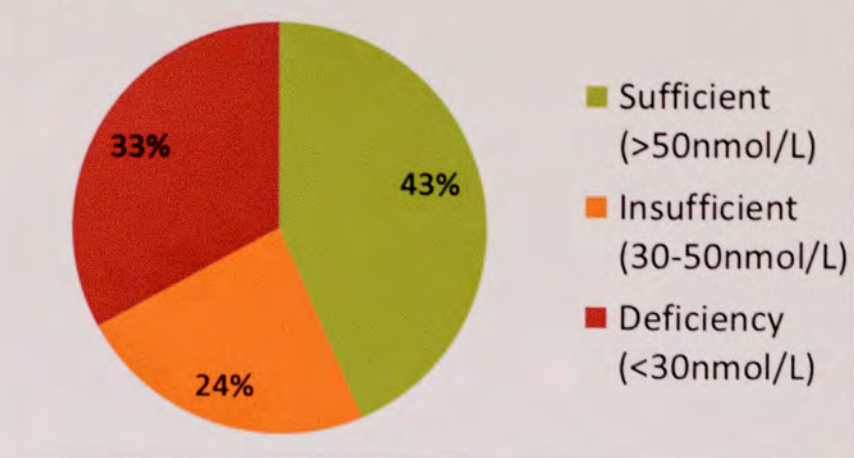


Figure 2:



## CONCLUSION

Deficiency levels in our cohort are in line with national estimates<sup>iv</sup> which would be expected in a cohort of patients that are following a strict gluten free diet and at low risk of malabsorption. We see promoting good bone health as a key role of the annual review service and knowing our patient's vitamin D levels can ensure we are giving appropriate advice.

In future, we will continue to measure vitamin D levels in our newly diagnosed and established coeliac patients; we will recommend vitamin D treatment to:

- All patients in the deficiency range
  - All patients in the insufficiency range with demonstrated reduced bone density, or who are more likely to have malabsorption due to a raised Tissue Transglutaminase
- We will continue to offer advice regarding prevention on vitamin D deficiency to the rest of our cohort.

As we repeat this data collection in winter 2018/9 we hope to see a reduction in the rate of deficiency for patients previously measured and treated.



# Assessing Gluten Free Diet Adherence using CDAT and Biagi Questionnaires in Patients with Coeliac Disease

EMR Baggus<sup>1</sup>, A Rej<sup>1</sup>, MS Lau<sup>1</sup>, PD Mooney<sup>1</sup>, MA Rees<sup>1</sup>, WL White<sup>1</sup>, LJ Marks<sup>1</sup>, M Hadjivassiliou<sup>1</sup>, DS Sanders<sup>1</sup>  
<sup>1</sup>Academic Unit of Gastroenterology, Royal Hallamshire Hospital, Sheffield Teaching Hospitals, UK

## Introduction

The gold standard currently for assessing adherence in individuals with coeliac disease is via duodenal biopsies to assess for histological remission. This is invasive and costly, but is required as there is currently no reliable surrogate marker for predicting villous atrophy in these patients.

## Aims

To assess the utility of the CDAT and Biagi questionnaires for non-invasive assessment of gluten free diet adherence.

## Methods

Patients with an established diagnosis of coeliac disease, referred for further evaluation of dietary adherence and disease remission were assessed between January 2016 to December 2018. Patients were prospectively recruited, and completed CDAT and Biagi questionnaires, with at least 4 duodenal biopsies taken from D2 in addition to at least one biopsy from the duodenal bulb. The presence (Marsh 3a or above) or absence (Marsh 0-II) of villous atrophy was used to determine the sensitivities of the tests.

Figure 1 | Biagi questionnaire<sup>1</sup>

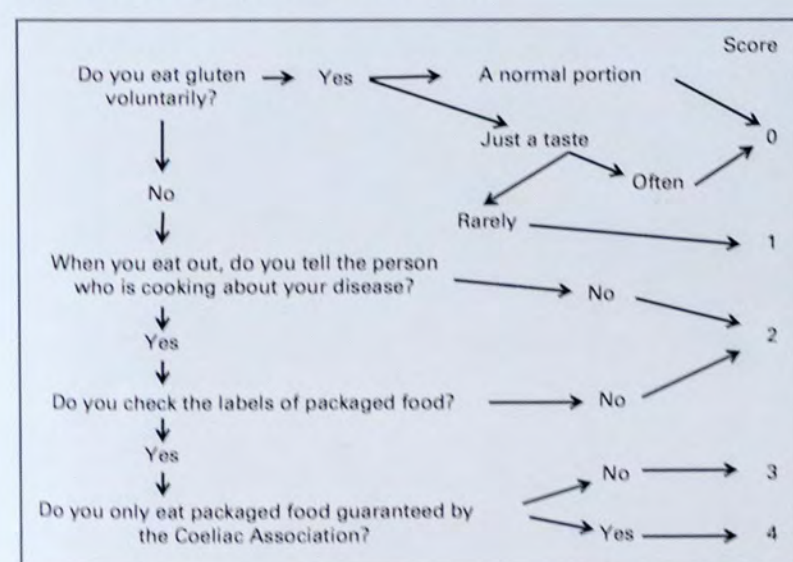


Figure 2 | CDAT questionnaire<sup>2</sup>

Question	1	2	3	4	5
Have you been bothered by low energy level during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by headaches during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
I am able to follow a GFD when dining outside my home	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Before I do something I carefully consider the consequences	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I do not consider myself a failure	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
How important to your health are accidental gluten exposures?	Very important	Somewhat important	Neutral/unsure	A little important	Not at all important
Over the past 4 weeks, how many times have you eaten foods containing gluten on purpose?	0 (never)	1-2	3-5	6-10	>10

## Results

151 patients were recruited, 101 females (66.9%), median age 55.0 years, median duration of GFD of 72.0 months. Table 1 outlines the sensitivity and specificity of the CDAT questionnaire, Biagi questionnaire, IgA-TTG and IgA-EMA.

Table 1 | Sensitivity and specificity of adherence questionnaires compared to serology.

	Sensitivity% (CI)	Specificity% (CI)	Positive predictive value % (CI)	Negative predictive value % (CI)
CDAT	52.0 (37.6-66.1)	69.8 (60.9-77.5)	40.6 (28.8-53.6)	78.6 (69.6-85.5)
Biagi	22.4 (12.2-37.0)	93.1 (85.6-97.0)	61.1 (36.1-81.7)	71.4 (62.8-78.8)
CDAT & Biagi	61.2 (46.2-74.8)	69.3 (60.5-77.2)	43.5 (35.3-52.0)	82.2 (76.2-87.0)
IgA-TTG	30.6 (18.7-45.6)	91.6 (83.6-96.0)	65.2 (42.8-82.8)	71.9 (62.8-79.5)
IgA-EMA	34.3 (26.7-42.7)	92.5 (84.8-96.7)	68.2 (45.1-85.2)	71.9 (62.9-79.5)

## Discussion

The sensitivity of the CDAT questionnaire was not superior to IgA-TTG for predicting villous atrophy in patients with coeliac disease. However, the use of a combination of both Biagi and CDAT had a greater sensitivity than IgA-TTG and IgA-EMA ( $p < 0.05$ ), but lower specificity ( $p < 0.05$ ). Duodenal biopsy remains the gold standard, although these scores remain useful tools in the assessment of dietary adherence.



# Assessing Gluten Free Adherence Using Gluten Immunogenic Peptides In Coeliac Disease: First UK Pilot Study

A Rej<sup>1</sup>, EMR Baggus<sup>1</sup>, G Wild<sup>1</sup>, DS Sanders<sup>1</sup>

<sup>1</sup>Academic Unit of Gastroenterology, Royal Hallamshire Hospital, Sheffield Teaching Hospitals, UK

## Introduction

Adherence to a gluten free diet (GFD) is essential, as poor adherence can lead to persistent villous atrophy and subsequent complications of coeliac disease (CD). We have previously shown<sup>1</sup> that non-invasive markers of adherence have a poor sensitivity in comparison to the gold standard of duodenal biopsy. As a result of this, we assessed the novel technique of gluten immunogenic peptides (GIP) in the urine.

## Methods

Patients with coeliac disease, both new diagnosis and those referred to secondary care for further evaluation of dietary adherence/disease remission were assessed from September 2018 to December 2018.

Patients were tested for GIP using a rapid immunochromatographic test, following the collection of mid-stream urine samples. All patients were also tested for tissue transglutaminase (IgA-TTG) and endomysial antibodies (IgA-EMA) via blood tests.

At least 4 duodenal biopsies were taken from D2 and at least one biopsy from the duodenal bulb, with the presence/absence of villous atrophy used to determine the sensitivities of the tests.

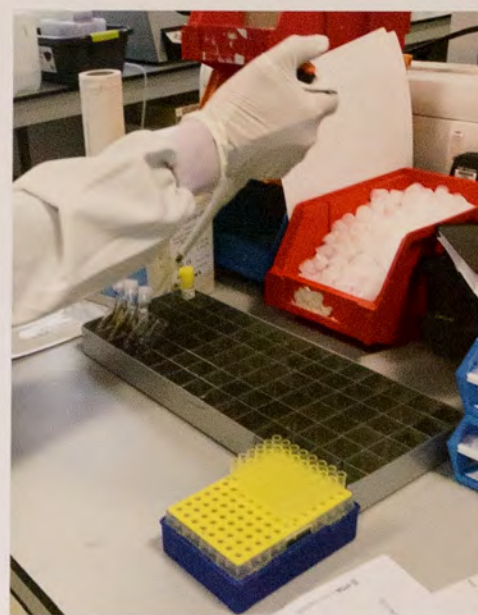


Figure 1 Urine samples being analysed



Figure 2 (a) Negative GIP (b) Positive GIP

## Results

17 patients were recruited (n=12 female, 71%), median age 52 years (range 25-74 years), median duration of GFD 96 months (0-840 months). 2 patients were newly diagnosed CD, 15 patients were established diagnosis of CD. Table 1 outlines the sensitivity and specificity of GIP, IgA-TTG and IgA-EMA.

Table 1 | Sensitivity and specificity of adherence tests

	Sensitivity% (CI)	Specificity% (CI)	Positive predictive value % (CI)	Negative predictive value % (CI)
GIP	66.7 (24.1-94.0)	63.6 (24.1-94.0)	50.0 (17.4-82.5)	77.7 (40.1-96.1)
IgA-TTG	40.0 (7.3-83.0)	100.0 (67.9-100.0)	100.0 (19.8-100.0)	78.6 (48.8-94.3)
IgA-EMA	40.0 (7.3-83.0)	100.0 (67.9-100.0)	100.0 (19.8-100.0)	78.6 (48.8-94.3)

## DISCUSSION

Urine GIP testing was not superior to IgA-TTG or IgA-EMA. Further data is required to assess this modality as a predictor of villous atrophy and adherence before this can be used in clinical practice.



# Analysis of faecal **gluten immunogenic peptides** to confirm the gluten intake during the diagnosis of coeliac disease and the adherence to the gluten-free diet

Alfonso Rodríguez Herrera, Isabel Comino, Verónica Segura, Jacobo Díaz, Alba Muñoz-Suano, Ángel Cebolla, **Laura Coto**, Carolina Sousa and Deliac Group

## CONCLUSIONS

Faecal gluten immunogenic peptides (GIP) could be a valuable tool for Coeliac Disease (CD) management at different levels:

1. Confirmation of previous gluten challenge at diagnosis.
2. Monitoring short- and long-term GFD compliance, as serological tests had no significant sensitivity to assess the adherence to the diet.
3. Identification of real unresponsive CD from non-compliant patients.



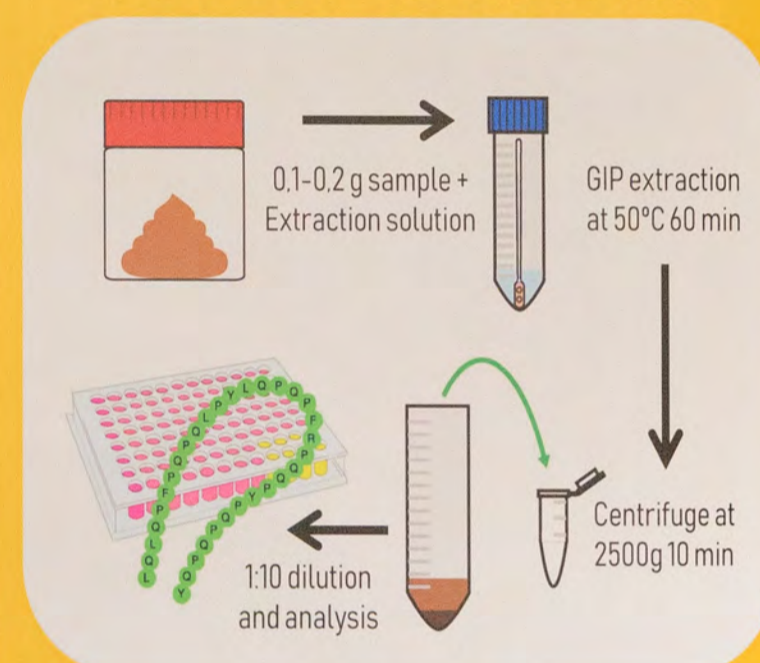
## BACKGROUND

A lifelong strict GFD is the only treatment for CD, but good compliance can be difficult for these patients. Furthermore, the current monitoring tools for GFD follow-up, such as dietary interviews and serology, do not offer an accurate measure to ensure the adherence to the diet. The aim of this study was to evaluate the measurement of GIP in stool as a marker of GFD adherence in CD paediatric patients.

## METHODS

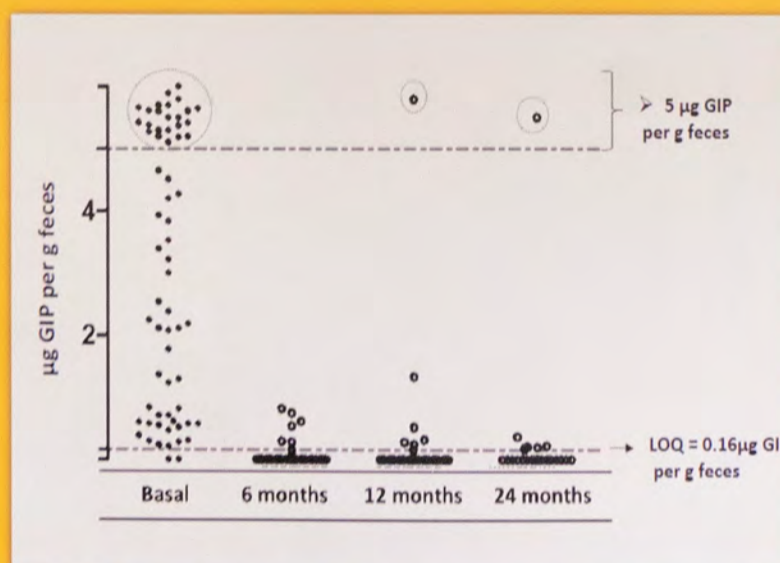
This multicentre prospective nonrandomized observational study included 64 CD children. Faecal GIP, anti-tissue transglutaminase (anti-tTG) and anti-deamidated gliadin peptide (anti-DGP) IgA antibodies were analysed at diagnosis and during follow-up visits at 6, 12 and 24 months. Correlations between GIP and serum antibodies were conducted by Cochran's and Friedman tests.

## FAECAL GIP MEASUREMENT

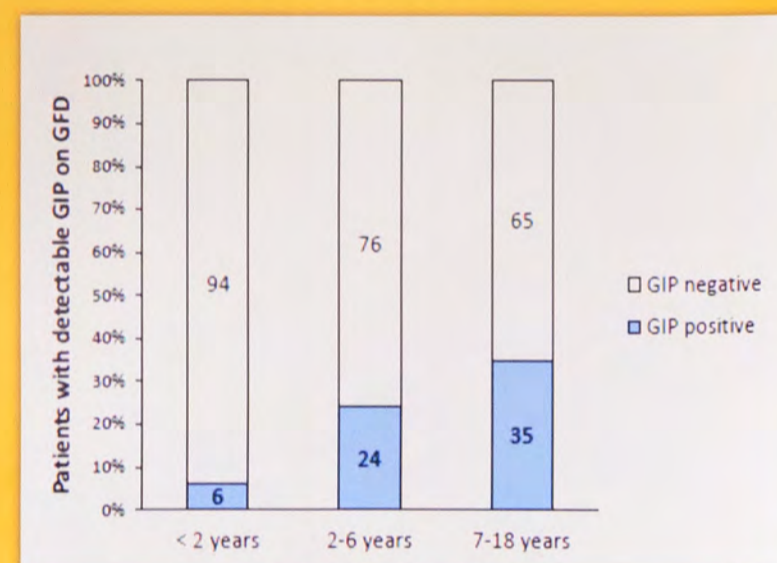


## RESULTS

Most children (97%) had detectable GIP at diagnosis, whereas only 23% had detectable GIP on a GFD. However, the rate of positive GIP stools increased from 13% to 25% during the follow-up (Figure 1), especially in older children (Figure 2). Despite patient dropout, the ratio of positive GIP was increasing and the highest positive results were found in the last visits (Figure 3).

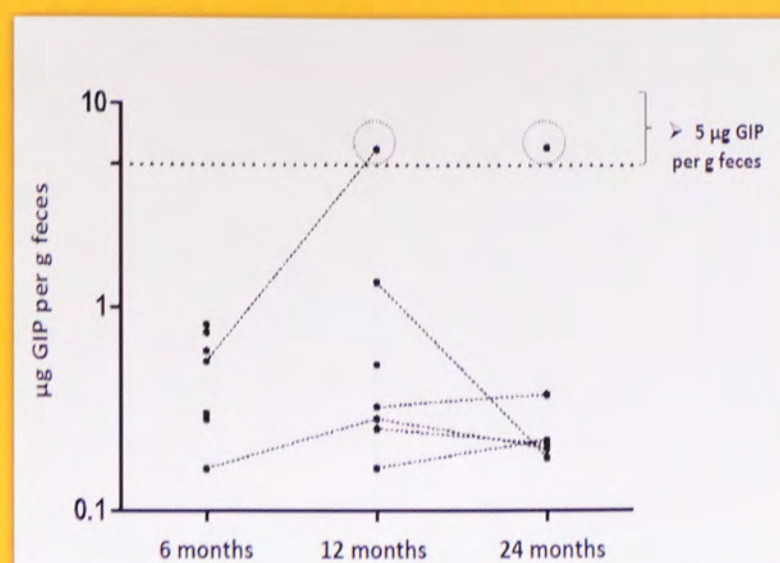


**Figure 1.** Evaluation of GFD adherence in coeliac paediatric patients according to GIP content in each follow-up visit (basal, 6, 12 and 24 months). Each point represents the mean of two replicates for each sample. LOQ, limit of quantification.

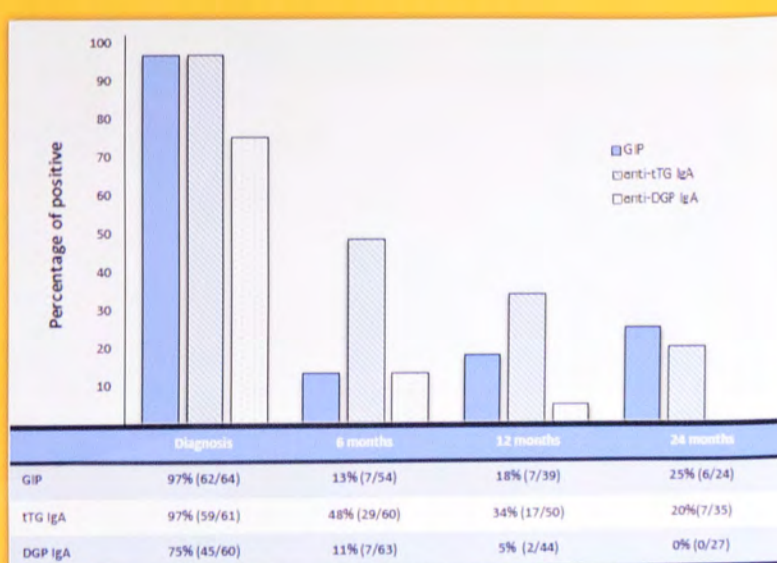


**Figure 2.** GFD adherence according to patient age. Percentage distribution of coeliac patients according to GIP concentration and age.

In contrast, anti-DGP normalised by 24 months and only 20% had elevated anti-tTG antibody. The elevation of anti-tTG antibody was more prolonged in patients with detectable GIP ( $p < 0.05$ ) (Figure 4). Nevertheless, serologic tests had low sensitivity to identify patients with detectable GIP considering absolute values ( $p > 0.1$ ).



**Figure 3.** Evolution of GIP positive results in coeliac paediatric patients in each follow-up visit. The lines are connecting the same patient.



**Figure 4.** Percentage of transgression of paediatric coeliac patients in the follow-up visits (basal, 6, 12 and 24 months) with the different methods used: GIP, anti-tTG and anti-DGP.



Satherley, R. King's College London, United Kingdom,  
 Coburn, S.S. Children's National Health System, Washington D.C.,  
 Germone, M. Children's Hospital, Colorado

# The Impact of Coeliac Disease on Caregiver's Well-Being and Quality of Life

A diagnosis of coeliac disease requires individuals to adopt a strict, gluten-free diet. Naturally younger patients must rely on their families for instruction, support and daily help with managing coeliac disease [1]. Therefore, coeliac disease may challenge the entire families well-being and quality of life.





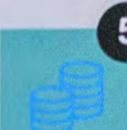
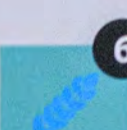


## Methods

A systematic review was conducted to provide insight into the challenges that families with coeliac disease may face.

Five databases were searched for papers that reported on: 1) caregivers of a child with coeliac disease; 2) with at least one outcome indicator assessing caregivers well-being or quality of life.



- 1  12 papers were included in the review
- 2  Results were reported across 615 caregivers
- 3  Caregivers reported impaired quality of life and well-being (11/12 papers)
- 4  Families reported avoiding travel and dining outside the home to accommodate their child's needs
- 5  Coeliac disease contributed to economic hardship and family conflict
- 6  Caregiver well-being was more impaired for non-adherent children (3/5 papers)

## Quotes from Families



We were going to put the whole family on the gluten-free diet but there's no way we can afford it.



I sincerely hope that the disease is not going to affect his coming life and be a hindrance to him.



I worry a lot when they're at school... [that] nobody will know what to do.



The term family is supposed to be supportive but with the coeliac disease, it became an area for frustration and disappointment.

[1] Bacigalupe, G., & Plocha, A. (2015). Celiac disease is a social disease: family challenges and strategies. *Families, Systems and Health*, 33, 45-54.



# THINK! COULD THEY BE HYPERVIGILANT?

Maintaining the gluten-free diet requires increased control around food, including monitoring of food labels and detailed questioning to avoid cross-contact with gluten containing food [1]. Adherence to the gluten-free diet is essential for those with coeliac disease.

Satheley, R. (Kings College London, Department of Population Health and Life Sciences) & Lerigo, F. (University of Birmingham, School of Psychology)

## 1 WHAT IS HYPERVIGILANCE?

Maintaining the gluten-free diet requires increased control around food. Sometimes, hypervigilance occurs when managing the gluten-free diet. This is characterised by food preoccupation, controlling behaviours and extreme vigilance [2].

## 2 WHY DOES THIS MATTER?

Hypervigilant approaches to gluten-free diet management have been linked to impaired quality of life, low mood, anxiety and eating disorders in adults and adolescents with coeliac disease [3].

## 3 DOES IT HAPPEN IN MY CLINIC?

These patients often describe good adherence to the gluten-free diet, and are typically not flagged as a cause for concern in clinic appointments

*I would never cheat on my gluten-free diet*

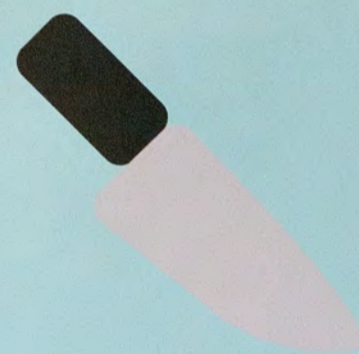
## 4 FINDING THESE PATIENTS

However, individuals with coeliac disease report hypervigilant approaches to managing the gluten-free diet that severely impairs quality life (n=12). Qualitative research was used to generate focused questions that may be useful for clinicians in identifying and understanding such patients.

## 5 KEY QUESTIONS TO ASK

Tell me about a time when you were concerned about cross-contamination

What did you do to manage this concern?



## 6 LOOK FOR: DELUSION-TYPE BELIEFS

*I found out there was flour in my car air bag... so I don't drive anymore*

*My husband out the wallpaper up but he forgot the wallpaper paste had gluten in it. I don't go in that room anymore*

## 7 LOOK FOR: IMPAIRED QUALITY OF LIFE

*I couldn't go to my cousins wedding because of all the food... staying at home keeps me safe*

*At work, I sit on my own for lunch... being near other people's bread crumbs scares me*

## 8 CLINICAL IMPLICATIONS

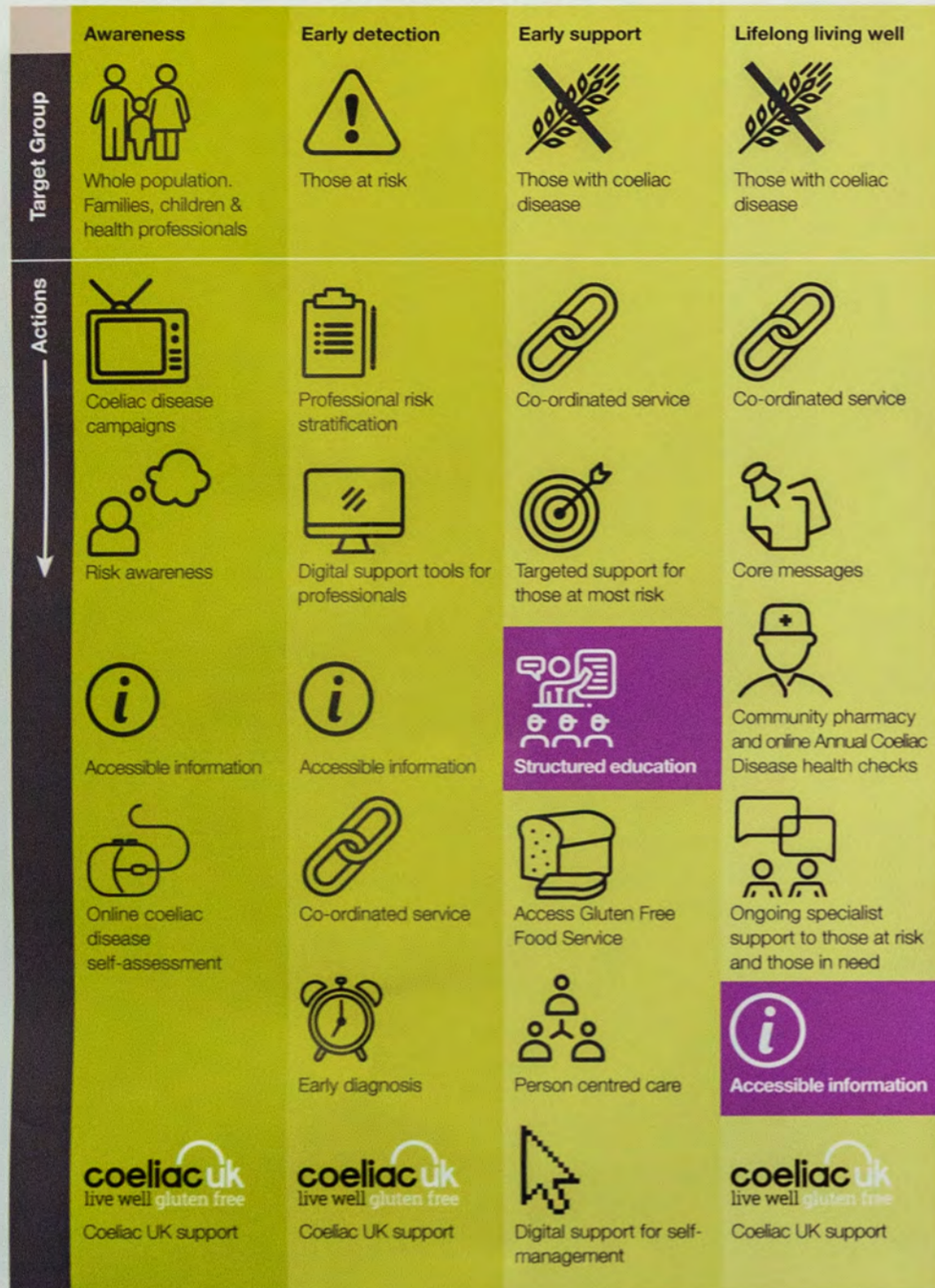
Strict management of the gluten-free diet is essential for those with coeliac disease, this needs to be balanced with patient well-being and quality of life.

Asking patients about the way they manage their diet, may shed light on our understanding of hypervigilance.



# Living well with COELIAC DISEASE...

## Framework at a glance



## Introduction

The Scottish Government has led the co-production of a new coeliac disease pathway for Scotland which aims to improve the experience people with coeliac disease receive, meets both Modern Outpatient Programme (Scottish Government, 2017) and Scottish Access Collaborative (Scottish Government, 2017) core principles, reduces health inequalities and provides best value for the NHS. During the co-assessment phase, greater access to online digital self-management support was identified. The Living Well resource was developed to meet the needs of supporting people after diagnosis (see highlighted area in coeliac disease framework).

## Method

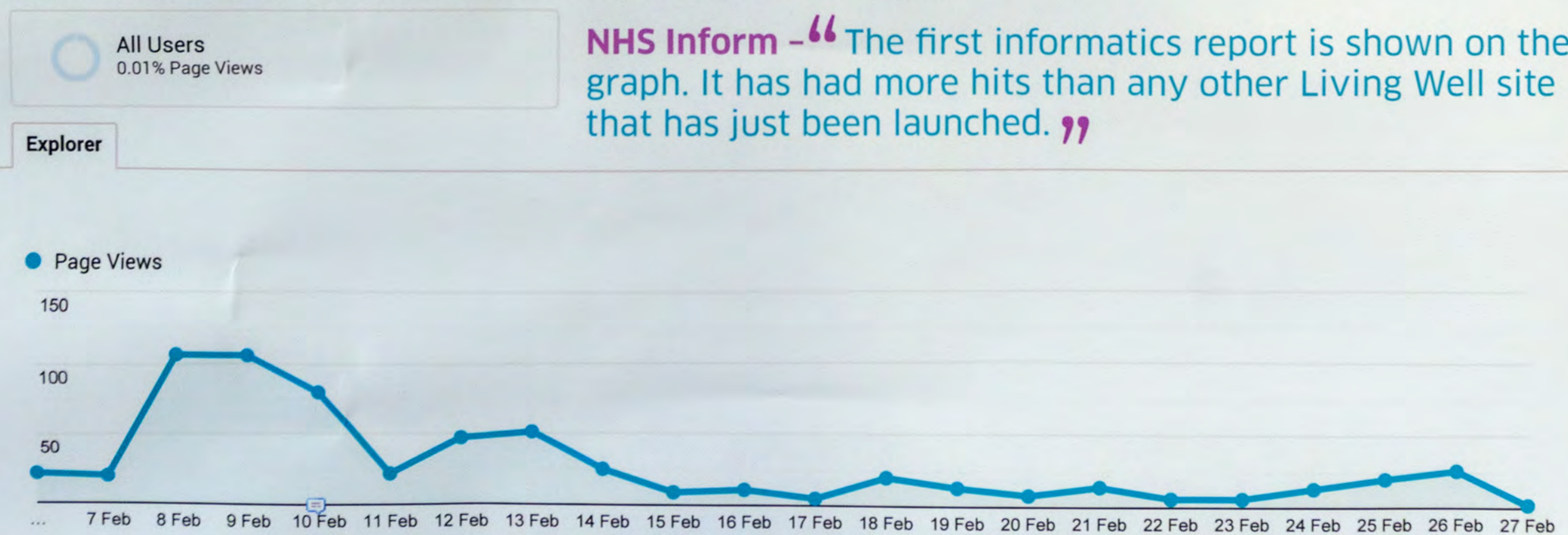
Working with key stakeholders the Scottish Government, NHS 24, Coeliac UK, GI Consultants, dietitians, and people living with coeliac disease, identified key messages people newly diagnosed would find helpful. Coeliac UK specifically worked with their members to develop the material. This included top tips and myth busting messages. Self-management materials were drafted and a film script was created. The film was delivered by a person living with and having experience of coeliac disease personally and as a parent. The material now forms part of a refreshed coeliac disease NHS Inform website which aims to give vital information to people at the early support and lifelong living stage of the new Scottish coeliac disease framework. It will be especially useful for newly diagnosed people transitioning from gluten to gluten free living.

## Results

The digital resource <https://www.nhsinform.scot/illnesses-and-conditions/stomach-liver-and-gastrointestinal-tract/coeliac-disease/living-well-with-coeliac-disease> was created. Feedback on the resource captured in the NHS Inform site will be collected over the next few months to ascertain the usefulness of this resource to both clinicians and people living with coeliac disease. The film link has been incorporated into the 'once for Scotland' dietetic coeliac disease intervention currently under development. The site went live on the 7th February 2019 and Google information as shown in Graph 1 has shown good traffic especially after the press release.

Dietitian - "Just had a read through and watched the video - absolutely fantastic!"

Graph 1: Informatics from coeliac disease living well NHS inform pages



## Discussion

Co-production has resulted in key stakeholders delivering quality self-management information to citizens in a unique digital setting and on a 'once for Scotland' basis. The resource should encourage people living with coeliac disease to live well with their condition and provides positive advice for newly diagnosed on living with coeliac disease and managing a gluten-free lifestyle.

## Conclusion

The site has just been launched and the early data suggests that it is being used. Clinicians feel this is a useful adjunct to their care and are signposting people to it for support.

Dietitian - "a good summary of everything we go through in dietetic group education session so it is a good reminder for people."

### References



# 'Why can't we have what we need?': exploring the impact of prescribing changes for gluten-free foods in coeliac disease

Helen Crocker<sup>1</sup>, Mara Violato<sup>1</sup>, Thomas Lewis<sup>2</sup>, Crispin Jenkinson<sup>1</sup>, Michele Peters<sup>1</sup>

<sup>1</sup>Nuffield Department of Population Health, University of Oxford

<sup>2</sup>Department of Psychology, University of Exeter



## Introduction

Historically, the English National Health Service has supported people with coeliac disease by providing prescriptions for gluten-free foods. In recent years, as the availability of gluten-free foods has increased, some Clinical Commissioning Groups (CCGs) have restricted or stopped this support, leading to inconsistencies in access across England. Therefore, the aim of this research was to explore the impact of changes to prescribing policies on adults with coeliac disease.

## Methods

In-depth, semi-structured interviews were conducted to explore the impact of prescribing policy changes. Interview participants were recruited from a pool of respondents to a related survey (reported elsewhere) who indicated their willingness to participate in an interview. While a maximum variation sample was sought, those from more deprived backgrounds or who no longer had access to prescriptions were oversampled, as the main aim of the study was to understand the impact of changes to prescribing policy. Interviews were conducted face-to-face (n=16) or over the telephone (n=8), audio-recorded with the participant's consent, and transcribed verbatim. A thematic analysis was conducted in NVivo.



## Results - participants

Twenty-four adults with coeliac disease participated in an interview, of which:

- 17 lived in **non-prescribing** CCG areas;
- 6 lived in CCG areas that prescribe according to **national guidelines**;
- and 1 lived in a CCG area with **restricted** prescriptions.

In areas where prescriptions were available, three participants chose not to receive them. Demographic details can be found in Table 1. Participants resided in areas reflecting a broad range of deprivation, but there was a skew towards areas of greater deprivation. All participants were White British.

Participant characteristic	Summary
Age (years)	18 - 84
Gender (n)	Female (13), Male (11)
Marital status (n)	Single (11), Married (9), Widowed (3), Divorced (1)
Household income	<£10,000 - £60,000
Employment (n)	Retired (11+), Full / part-time work (4), Self-employed (3), Permanently sick or disabled (3+), Full-time education (2), Unemployed (1), Volunteering (1)
Time since diagnosis (years)	<1 - 44

<sup>†</sup>One participant regarded themselves as permanently sick or disabled, and retired

Table 1: Summary of interview participant characteristics

## Results - themes

### (1) Frustrations about prescribing changes

- The decision to withdraw prescriptions was generally met with a strong sense of frustration and irritation, with a few participants reporting no or very short notice periods prior to their withdrawal. In two cases, people felt that they had been lied to by their Clinical Commissioning Group (CCG).

"I've made formal complaints because I feel they lied to us at [Town]. They said that because of government cutbacks that they'd done a consultation via, you know with other GPs and with coeliacs in the area etc. I asked for a Freedom of Information Act from them [but] I've never been given any proof that the consultation actually ever took place." (Participant 19, female, 47 years old)

"It makes other people see us as if we're faddy eaters even more ... now that the medical fraternity are saying basically, 'Well no, you don't need food on prescription, I just feel like they're exacerbating that ... because, you know if the GPs aren't even going to give you the medicine you need, prescription food, then why should the normal people out there understand.'" (Participant 19, female, 47 years old)

- With an increased number of people choosing to follow a gluten-free diet as a lifestyle choice, many participants wanted others to recognise their dietary needs as a medical necessity. A few participants felt the withdrawal of prescriptions compounded this issue.

- Some participants raised the issue of inequity within the health care system, questioning the fairness for continued support in certain health conditions while support for people with coeliac disease is withdrawn.

"I'm sure there are other diseases and illnesses that people have, and they get the necessary medication for on prescription ... So, why can't we have what we need? It's difficult to...I guess the government think it's a luxury. I don't think it's a luxury; I think it's a necessity." (Participant 14, male, 61 years old)

### (2) Coping and adapting to prescribing changes

- The majority of participants were coping with the withdrawal of prescriptions, however, some reported incurring increased food costs, and three reported that they are now eating less bread.

"The CCG took it off prescription because of cost, you know. I hardly ever use them anyway but, you know if I want some bread or rolls or something, I just buy them. Chucks them in the freezer, you know and use it as I need it, basically." (Participant 1, female, 68 years old)

"The system pulled the rug out from under us. So suddenly, you know I'm in a, from having the stuff brought right in to my kitchen in that whole thing of it becomes like the main reason I go out, which is to get my gluten-free food from somewhere; it's nothing else. That is my focus, is really all, well, I would say every time I go, get out I have to get something to fill the gluten-free gaps." (Participant 4, female, 69 years old)

- For three participants, the impact of prescribing changes was much greater, both in terms of food costs and the ability to obtain gluten-free substitute foods from elsewhere. Two were wheelchair users, and the other an 84-year old single man. A female wheelchair user with co-morbidities found the change particularly difficult (see quote).

- Interestingly, a 62-year old female, diagnosed for 15 years, commented that she "can't really see the point in people being diagnosed properly now" (Participant 18). Although only mentioned by one participant, it is interesting to consider whether a perceived lack of support from the NHS will deter individuals from seeking a formal diagnosis.

### (3) Future access to prescriptions

- While many participants acknowledged the financial challenges faced by the NHS, all participants thought that gluten-free substitute foods should be available on prescription. Some specifically stated that prescriptions should be limited to staple foods, although there was variation between participants about what this constitutes, with bread, flour, flour mixes, pasta and cereal all mentioned.

"I would value going back to having two or three basics that you need [on prescription]. I mean if I could have the oats I would be, it would change my life completely; honestly. With all this difficulty of getting it, that would be such a difference, it would make a massive difference because my whole life is now centred around trying to get that food, and the energy it takes to get it." (Participant 4, female, 69 years old)

- A voucher scheme was suggested by two participants as an alternative way in which the NHS could offer support. A single male talked fairly extensively about what this might look like, suggesting a means-tested allowance, from which units are deducted in exchange for goods from supermarkets or pharmacies. He continues:

"You know, the same way if you're on free eye glasses, you don't go to your doctor for it; you go to [Chemist] with your letter saying, 'I've got a thing that says I'm entitled to free eye, or I've got glaucoma,' or whatever. Well why can't you go to [Supermarket] then? I've got coeliac disease, I'm entitled to Free From breads, or whatever, and I don't get what's difficult about that. So, that would be useful." (Participant 8, male, age unknown)

## Discussion

While the majority of participants were no longer able to access prescriptions for gluten-free foods, most had developed coping strategies and adapted to prescribing changes. However, the impact of these changes was much greater for participants with mobility issues. It should be noted that participants selected for interview were more likely to be in favour of

prescriptions due to the sampling strategy used during recruitment. When reviewing prescribing policies, CCGs should consider retaining access to prescriptions for gluten-free foods. This would in particular benefit adults from more vulnerable groups who are disproportionately affected by the complete removal of prescriptions.