

**Citation for published version:**

A. M. Madden, A. M. Riordan, and L. Knowles, 'Outcomes in coeliac disease: a qualitative exploration of patients' views on what they want to achieve when seeing a dietitian', *Journal of Human Nutrition and Dietetics*, Vol. 29 (5): 607-616, October 2016.

**DOI:**

<https://doi.org/10.1111/jhn.12378>

**Document Version:**

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## **Outcomes in coeliac disease: a qualitative exploration of patients' views on what they want to achieve when seeing a dietitian**

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Key words: Coeliac disease, gluten free, outcome measures,

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All authors contributed to the design of the study, the analysis of the data and to the writing of the manuscript.

Conflicts of interests: The authors declare that they have no conflict of interests

Funding: British Dietetic Association General and Education Trust provided funding to undertake this study.

Acknowledgement: The authors thank the British Dietetic Association General and Education Trust for funding the study, Coeliac UK for contributing to the development of the topic guide and distributing invitations to participate, Heidi Urwin and Gill Shinkwin for expert comments on the study proposal and all participants who contributed through the interviews and focus groups.

## **Abstract**

### *Background*

Coeliac disease (CD) is managed by life-long adherence to a gluten-free diet and dietitians have the potential to facilitate this. Patient involvement through shared decision-making is central to behaviour-change skills used by dietitians but there is little evidence supporting its inclusion in evaluating dietetic interventions. The aim of this study was to explore patients' preferences for diet and nutrition-related outcomes in CD.

### *Methods*

Adults with CD or adult carers of children with CD were invited through support networks. Participants took part in a telephone, face-to-face interview or focus group which was audio-recorded and transcribed. Themes were developed using a framework method. Ethical approval was obtained.

### *Results*

Twenty-nine adult patients and five parents of CD children participated 0-34 years after diagnosis. Four main outcome-related themes emerged: (1) Participants wanted information specific to their lifestyle and time since diagnosis, focussing on food containing gluten, practical issues, prescribable items and general nutrition. (2) The degree of satisfaction with the consultation process impacted on participants' experience, including the dietitian's CD expertise, consistency of dietitian seen and the frequency and length of appointments. (3) Health concerns were important to participants and focussed on risk of osteoporosis, unwanted weight gain and the fat and sugar content of manufactured gluten-free products. (4) Clinical monitoring including bone scans and antibody measurements, were mentioned but were not described as being of importance for most participants.

### *Conclusion*

The outcomes preferred by CD patients and carers focussed primarily on information and resources received and satisfaction with their dietetic consultation.

## Introduction

Coeliac disease is a life-long small intestinal immune-mediated condition which is managed by adherence to a gluten-free diet<sup>(1,2)</sup>. Recent qualitative studies from the UK and Australia have identified the challenges faced by patients with coeliac disease when making changes to their diet in order to exclude gluten<sup>(3,4)</sup>. The participants in these studies provided mixed reports of the support they had received from dietitians. Although not specifically examined, this may reflect the limited access to dietitians and particularly to those with specialist knowledge and experience of coeliac disease that is recommended<sup>(5)</sup>. The provision of dietetic services to coeliac disease in the UK in 2007 was estimated to be approximately one third of that required to meet the provision recommended by the British Society of Gastroenterology<sup>(6)</sup>. These findings, combined with increasing prevalence of coeliac disease, which is considered to be independent of improvements in diagnosis<sup>(7)</sup>, suggest that there is a shortfall of dietitians working in this area.

Research recommendations made by the National Institute for Health and Care Excellence (2015) include identifying how dietitians can contribute most effectively to the management of coeliac disease within the healthcare team<sup>(5)</sup>. In order to address this and to support the commissioning of coeliac specialist dietitians, evidence is required to indicate that investment of resources in this area might yield improved outcomes. Outcome measures in coeliac disease are usually based on a medical model which includes measuring serum IgA tissue transglutaminase (tTG) and IgA endomysial antibodies (EMA) and repeat biopsies<sup>(5,8)</sup> or evaluated by an audit of procedures<sup>(9)</sup>. Complementing these, but not explicit in outcome measures, is patient involvement through shared decision-making and this is embedded in the quality standards of NHS care<sup>(10)</sup>. Taking patients' preferences into account when determining outcomes may help to identify areas on which to focus dietetic interventions and this is compatible with current health strategies<sup>(11)</sup>. This approach is supported by development of patient reported outcome measures (PROMs) which identify health outcomes that are valued by patients. PROMs enable the effectiveness of care to be assessed from a patient's perspective<sup>(12,13)</sup>. Although PROMs have been used to compare assessments of variables such as mobility and pain after elective surgery, thus creating a measure of effectiveness of treatment<sup>(12,14)</sup>, there are few reports of diet or nutrition-related PROMS<sup>(15)</sup> and

quality of life surveys in coeliac disease have not focussed on diet or nutrition<sup>(16,17)</sup>. A recent study investigating the outcome preferences of patients with liver disease indicated their interest in this area and provides a model for exploration that can be utilised in other patient groups, for example in coeliac disease<sup>(18)</sup>.

The aim of the proposed study is, therefore, to identify the preferences for diet and nutrition-related outcome measures of patients with coeliac disease and their carers.

## Methods

*Participants and recruitment:* Adult patients with coeliac disease and adult family members or carers of patients with coeliac disease were invited to participate in a semi-structured interview or focus group by invitations circulated by a national coeliac support charity, Coeliac UK, or via local support groups. Initial responses were predominantly from White women so a second targeted email invitation was sent to approximately 476 coeliac patients who were male or from Black Minority Ethnic backgrounds. Inclusion criteria for participation included age  $\geq 18$  years and ability to speak English. Potentially interested participants were provided with an information sheet and given the opportunity to ask questions. Those agreeing to participate then gave written consent.

*Data collection:* Each participant took part in a face-to-face interview, telephone interview or focus group depending on their choice and arranged at a mutually convenient time and location. A topic guide was developed collaboratively with input from adults with coeliac disease and those with expertise in working in this area. The guide was then used to direct questions and discussion in all interviews and focus groups which were led by the same researcher. A second researcher was present during the focus groups. All data collection sessions were digitally audio recorded and the recordings transcribed outside the research team using a secure research transcription service. Field notes and a diary were kept by the lead researcher and used to reflect on the process of data collection in order to maximise open and independent conversation while maintaining focus on the study aim. Recruitment of participants continued during data analysis until saturation, i.e. no further new themes emerged<sup>(19)</sup>.

*Data analysis:* The transcribed records were read as soon as available by the lead researcher, the second researcher, who participated in the focus groups, and by a third researcher who did not participate in data collection. All three researchers were registered dietitians with varying expertise in coeliac disease. The transcripts were examined using the framework method<sup>(20,21)</sup> using five distinct stages<sup>(22)</sup>: (1) familiarization included each researcher reading and re-reading the transcripts and making notes independently; (2) development of the thematic framework was undertaken during repeated discussion between the three researchers where notes

were shared and emerging themes mapped, discussed and then revised; (3) indexing of themes was undertaken by the lead researcher; (4) charting and synthesising of themes was undertaken manually following further discussion and using an online spreadsheet; (5) finally, the charts were mapped and interpreted so that themes could be linked and illustrative quotations identified.

*Ethics:* Permission for the study was obtained from the University of Hertfordshire Ethics Committee.

## Results

Twenty-nine adults (ten men, nineteen women) with coeliac disease and five adult carers of children with coeliac disease participated. Twenty-three adult patients and all five carers participated in an interview, all of which were undertaken by telephone except one which was conducted face-to-face. The remaining six adult patients took part in two focus groups each comprising three adults. The mean  $\pm$  standard deviation ages of the adult patients and children were  $55.4 \pm 14.9$  and  $10.8 \pm 4.1$  years respectively and interviews were undertaken a mean of  $7.4 \pm 8.4$  (range 0-34) years after diagnosis with coeliac disease. All participants were of White European background. All interviews lasted between 20-50 minutes and the focus groups lasted 60-75 minutes.

Participants' responses varied with their individual needs and existing knowledge at the time of the consultation and their own health concerns. Their preferred diet and nutrition-related outcomes were summarised into four main themes (Table 1): knowledge and information received, the degree of satisfaction with their dietetic consultation, concerns about health and clinical monitoring.

### 1) *Knowledge and information received*

*Food items:* All participants expected to improve their knowledge about the gluten-free diet after seeing a dietitian: *'I just wanted some more help with the diet'* (CD002). This was defined as wanting to know which foods to eat or not to eat including fresh, prepared and packaged foods. Detailed clarification about eating oats was required: *'I was keen ... to understand about oats and how that would work with a child'* (CD012). Other participants wanted to know how to combine the diet with other restrictions including vegetarian, cultural requirements or food allergies: *'I was hoping she would tell me what I could eat and also a little bit more about my allergies'* (CD006). The level of existing knowledge effected the participants' responses with some being very satisfied: *'I was absolutely bowled over with the level of detail'* (CD018) whilst others were not: *'a lot of information I was given I'd already come across from searching online'* (CD004) and *'he hardly answered any of my questions'* (CD015).



*Resources:* Receiving resources from the dietitian such as leaflets and postcards for requesting gluten-free food samples, being directed to Coeliac UK and an allergy fair were considered a positive experience. The standard of leaflets varied and often did not meet expectations: *'she gave me a sheet ... it wasn't really much use'* (CD007) and another participant hoped *'to get something a bit more tailor-made'* (CD015). Concern was expressed by one participant who received a sheet that highlighted high calcium foods but also listed foods containing gluten. Receiving resources that combined different prescribed diets, such as diabetic and lactose free, was identified as being an important but sometimes unfulfilled outcome with some dietitians described as not having enough knowledge to provide this.

*Condition:* Most participants commented that it would have been helpful to have known more about their condition at the initial consultation: *'...dietitians need to be more exact in explaining ... you can't dip in and out, you're a coeliac or you're not ...'* (CD015) and *'I had not realised the importance of following the diet'* (CD027). Participants had varying experiences with some gaining information about their condition from medical consultants but others expected their dietitian to provide this. Receiving more information about gluten sensitivity and the genetic risk associated with coeliac disease was also identified as preferred diet and nutrition-related outcomes.

*Gluten-free foods:* Participants frequently referred to their desire for accurate information about their prescription entitlements and one explained that *'the only thing I wanted to do was to sort out my prescription'* (CD003). Different prescription allowances across the country were identified as being unfair and confusing and some dietitians' knowledge of this was considered to be out-of-date: *'the dietitian should have been more aware about the prescription allowances in [our NHS Trust]'* (CD017). Difficulty in changing prescriptions was frequently mentioned and one participant commented that *'you don't need a medical degree to [prescribe food]'* (FG02). Participants commented that biscuits and cakes were a luxury but that bread and bread mixes were essential in managing their diets. The pre-payment certificate was mentioned as being helpful financially although one person commented that they found out *'how to get an HC2 form to get food prescriptions but nobody advised me ... that would have been useful'* (CD001). Concern was

frequently raised about the ingredients in manufactured gluten-free foods, especially sugar: *'a lot of pastas haven't got sugar in but the one we've been getting on prescription has'* (CD011) and *'just be aware that it's got a shed-load of sugar in'* (CD019). Other ingredients that were described as being of concern were the perceived amount of fat and salt in foods and inclusion of other 'chemicals' (FG02). Many participants expressed that it would have been useful if their dietitian had made them aware of the energy-content of gluten-free biscuits and cakes.

*Practical issues:* Some participants were hoping for more practical advice about gluten-free food availability in their home area. Dietitians who provided details, for example, *'a list of local butchers'* (CD018) that sold gluten-free sausages or fish and chip shops with *'special evenings for coeliacs'* (CD017) were considered very helpful. Others identified that the cost of food was a major concern: *'no-one warned me about how expensive everything was...'* (CD015) and *'for people on a budget the dietitian could help much more'* (CD009). Participants welcomed help with snacks, recipes and meal ideas and suggested the dietitian could have provided more recipes for 'light meals'. The risk of contaminating gluten-free food with gluten from other dietary items during preparation or when eating away from home was described as an important topic that dietitians should highlight: *'avoiding contamination ... in the kitchen particularly ... was the strongest message I got'* (FG02). Parents valued help from a dietitian in communicating their child's dietary needs to others, for example, *'if there was a sheet we could hand [to] school'* (CD011).

*Nutrition:* A large number of adults were concerned about unwanted or excessive weight gain following initiation of a gluten-free diet and this linked with comments about the nutritional content of gluten-free foods: *'...really concerned about how fast the weight's coming on'* (CD015) and *'for the first time in my life ... I've had to worry about my weight'* (CD002). There was some concern about the overall nutritional content of the gluten-free diet and an expectation that dietitians would address this: *'... what I hope[d] to get from the dietitian was: Am I still getting the same nutrition from this food as I was getting from my ... healthy diet before?'* (FG02). Participants described the importance of their diet providing specific micronutrients and the dietitian's role in monitoring this: *'the dietitian will go through the diet and ... in*

*particular ... focus on iron and calcium*' (CD012). Calcium and vitamin D intake was recognised as being related to long-term health such as osteoporosis risk: *'... [the dietitian] said about ... needing more calcium*' (CD010). One participant's preferred outcome was to know how to eat a nutritious gluten-free vegetarian diet: *'I want to really get this right, I want to make sure I'm eating the right things, getting the right balance*' but this was not achieved as the dietitian *'was only able to tell me what I could and couldn't eat*' (CD010). Requests for nutritional information relevant to specific life stages were also mentioned by some participants with reference to pregnancy, weaning, childhood and *'whether there are any complexities with ... aging*' (CD019).

## 2) Satisfaction with the consultation

*Dietitian:* Participants commented on many aspects of their consultations including the dietitians they had seen. Their overall experience varied from being extremely positive *'she was very thorough ... quite knowledgeable*' (CD022) and *'brilliantly useful*' to being quite negative *'I knew more than she did*' (CD019). Participants appreciated a personalised and flexible approach and wanted to have confidence in their dietitian. One parent commented: *'the support I received from the dietitian was above and beyond anything I'd expected*' (CD012). Participants were asked about whether their expectations were met but many could not answer this. Other responses varied from *'the dietitian was much better than I was expecting*' (CD003) to *'quite disappointed*' (CD025). Reassurance from the dietitian was seen as important: *'I don't know that I learnt an awful lot from it but I think it's reassuring ... to know I'm on track*' (CD002). Several participants mentioned that they had seen different dietitians and that some were clearly more knowledgeable than others. Expertise in coeliac disease was identified as being important: *'It wasn't her specialism ... so she issued me with a diet sheet*' (CD018) and *'It seemed insane to me [that] I had to wait almost two years to meet someone who really understood the condition*' (CD015). Participants preferred to see the same dietitian at each appointment *'I think the continuity of care is important*' (CD013) and *'it would have been great if I'd had ... the same person building up that rapport*' (CD004).

*Timing and frequency of appointments:* The timing of the consultation following diagnosis was considered important but this was often constrained by the availability

of appointments. Although participants considered that it was *'important to see somebody quickly'* (CD005) many reported that they had to wait, for example one child *'was diagnosed in November and we've literally only just seen a dietitian in the last month [March]'* (CD023). In most cases, the longer a participant had to wait to see a dietitian, the more informed they became through self-exploration and the outcomes they preferred were different from those who were recently diagnosed. For many participants, the perceived usefulness of the first consultation influenced whether they requested or attended follow up appointments: *'I found the first appointment quite helpful so I thought I'd go along to the other'* (CD017). Others suggested dietitians should be available for email follow up and for answering questions by telephone as face-to-face appointments could be *'quite disruptive because the hospital was in a different place [from] where I worked'* (CD028).

### 3) Concerns about health

*Short-term:* Most participants recognised the rapid improvement of short-term symptoms such as tiredness, diarrhoea, abdominal pain and bloating, weight loss and general ill health once they excluded gluten from their diet: *'... after six months of being on a gluten free diet ... I did feel so much more energetic'* (CD019) and *'... I wasn't bloated anymore ... it's a nice feeling not to have those [stomach] pains'* (CD025). Other short-term concerns before diagnosis included neurological symptoms described as *'brain fuzz'* (CD005) or *'the coeliac [disease] did something to my brain'* (CD009) but these symptoms responded to *'eliminating gluten from my diet and I've got my brain back'* (CD005). Although participants were able to describe these short-term improvements, they did not always express these in terms of preferred outcomes after seeing a dietitian.

*Long-term:* Some participants expressed concerns about their long-term health and these most often included osteoporosis, becoming overweight, damage to gastrointestinal villi and, occasionally, the *'risk of cancer of the gut'* (FG01). Again, these concerns were not directly expressed in terms of preferred diet and nutrition-related outcomes even though many participants also described the importance of calcium in the diet and their concerns about the perceived high quantity of fat, sugar and salt provided by some manufactured gluten-free products (see above).

#### 4) Clinical monitoring

A range of investigations relevant to managing coeliac disease were described by participants and whilst some related these to their dietitians' involvement few expressed them as preferred outcome measurements following a dietetic consultation.

*Diet diaries:* Participants gave mixed comments about keeping food diaries before a consultation ranging from *'I was asked to do a food diary which I did do and it wasn't looked at'* (FG01) to *'I thought it was a really useful feedback'* (FG01). Another who was not asked to complete a food diary suggested *'it might be helpful if they actually look at what you are consuming to see how balanced it is'* (FG01).

*Blood tests:* Some participants showed awareness about antibody, vitamin and mineral blood levels and this increased as time progressed from diagnosis and one dietitian was described as arranging *'for me to have some more blood tests'* (CD003). Although another participant hoped that *'the antibodies [have] come down ... that would reaffirm to me that the diet's working'* (CD021), most did not relate these directly to their diet. During the focus group discussions, it became apparent that some participants were not aware of the relevance of antibody testing nor that they could have these tests.

*DEXA scans:* Several participants described being referred for a DEXA scan to evaluate bone density and a few identified the dietitian's role in both requesting this: *'she ... sent me for a DEXA scan'* (CD003) and explaining the reason: *'the consultant actually sent me for a DEXA scan but the dietitian sort of explained ... why it was necessary'* (CD017). However, most individuals did not consider DEXA scans to be part of their dietetic consultation and did not express a preference for this outcome measure.

## Discussion

The predominant outcomes described by many participants focussed on the theme of increasing their knowledge in various areas by receiving relevant information from their dietitian. This preference for receiving information and improving knowledge during a dietetic consultation has been previously identified by patients with liver disease who completed an online questionnaire<sup>(18)</sup>. Although the methodology of the two studies differs, both highlight the importance of cognitive aspects of the dietetic consultation to those who participated. The relevance of patients' knowledge has been demonstrated in 390 adults with coeliac disease in Australia where a higher knowledge score was associated with better adherence to a gluten-free diet assessed by questionnaire<sup>(23)</sup>. However, improving knowledge through an online intervention did not improve adherence<sup>(24)</sup> and it is well-recognised that increasing knowledge alone is not sufficient to facilitate dietary behaviour change<sup>(25)</sup>. To contribute to this, empowerment of patients through facilitating their independent decision-making through relevant knowledge and understanding of both their condition and associated lifestyle changes is required<sup>(26)</sup>. This is of great importance in long-term conditions like coeliac disease where the basis of management is adherence to a gluten-free diet. Empowerment has been widely explored and utilised as a management strategy in other long-term conditions including diabetes<sup>(27,28)</sup> and although its importance in coeliac disease is recognised<sup>(29)</sup> there are fewer studies in this area<sup>(30)</sup>.

The participants in the present study described in detail the different types of information they required and while some was generic (i.e. which foods contain gluten) others were very specific (i.e. which local butchers sell gluten-free sausages). This level of detailed information may be impossible for dietitians serving a wide geographical area to provide but, from an empowerment perspective, it may be preferable to provide guidance about how the patient could explore these questions themselves, for example through local support groups. Dowd et al<sup>(31)</sup> has suggested that self-efficacy in coeliac disease can be enhanced through providing opportunities for patients to choose gluten-free foods in a guided environment, through role-modelling and verbal support in the food choice and this could be facilitated by dietitians engaging with support groups.

Participants' satisfaction with their consultation with a dietitian impacted on their overall experience and whether they were likely to attend future appointments. Similar views have been expressed by patients with diabetes who did not attend structured education sessions where the most common reason for non-attendance was lack of perceived benefit<sup>(32)</sup>. The responses from participants in the present study indicated that they preferred to see a dietitian with a high level of expertise in coeliac disease and a flexible approach that tailored advice to the individual. Appointments with an inexperienced or poorly-skilled dietitian were not valued especially if perceived to be delivering standardised information. The importance of relevant dietetic expertise is recognised in recent UK guidance which states that patients with coeliac disease should be provided with advice and education from an experienced dietitian<sup>(5)</sup>. However, it is acknowledged that access to specialist dietetic support is currently poor<sup>(5,6)</sup> and that patients may value other sources of information about a gluten-free diet more highly than from a dietitian<sup>(33)</sup>. Participants in the present study preferred to see the same dietitian at follow up appointments and this preference for continuity of care has been investigated in other areas of healthcare where continuity is associated with some benefits, including increased patient satisfaction, but with no detrimental effects<sup>(34)</sup>. Participants who had experienced remote dietetic follow up via telephone and email contact reported this positively especially if these replaced face-to-face appointments that required travelling some distance or taking time off work. This dietetic approach has not been evaluated in coeliac disease but in other areas of gastroenterology, it has been identified as potentially enhancing management<sup>(35)</sup>. Adopting and evaluating remote follow up may help address both continuity of care and access to a specialist dietitian.

Participants' outcome preferences related to health concerns differed with some expressing the need to address symptom management and undesired weight loss at diagnosis while others focussed on long-term health, particularly the risk of osteoporosis and unwanted weight gain. It is likely that health concerns vary with the time between diagnosis and the dietetic consultation and although this was discussed by participants it was not systematically evaluated in this qualitative study.

Participants' concern about unwanted weight gain, their overall nutritional intake and the perceived excessive fat, sugar and salt content of manufactured gluten-free foods is important and provides an opportunity for dietitians to provide more general healthy eating guidance rather than focussing solely on avoidance of gluten. Obesity in patients with coeliac disease who are adhering to a gluten-free diet has been reported but the prevalence is lower than in comparable non-coeliac populations<sup>(36,37)</sup>. It is possible that participants' concerns about sugar intake may have been triggered by the widespread media interest that surrounded revised guidance on dietary carbohydrate which was published during data collection<sup>(38)</sup>.

Most participants did not describe clinical monitoring, for example using DEXA scan, histological response or antibody results, as outcomes they expected to achieve following a consultation with a dietitian and some were not aware of the role of these investigations. This relatively low preference is comparable to that of patients with liver disease who also rated clinical monitoring, using different procedures, as less important outcomes when seeing a dietitian<sup>(18)</sup>. However, a few participants in the present study expressed interest in their test results and how these might be influenced by dietary adherence. This variation may reflect different levels of patients' interest and self-exploration or different approaches used by different management centres. Although this area is worth clarifying, clinical monitoring was not viewed as an important outcome in relation to dietetic consultations by most participants.

This study has some limitations that need to be considered before the evaluation of diet and nutrition-related outcomes identified can be further explored. Firstly, the population in this qualitative study was self-selected and not representative of people with coeliac disease in the UK and so their responses cannot be generalised. Efforts were made to engage with men and women from all ethnicities but, in spite of additional email invitations to adults from Black Minority Ethnic backgrounds, none responded. Undertaking most of the interviews by telephone rather than face-to-face meant non-audible communication could not be evaluated but this method allowed participants from a wide geographical area to contribute and may have helped them to feel relaxed and able to speak more freely in a place of their choosing<sup>(39)</sup>. The researchers who collected and analysed the data were all experienced dietitians



which enabled them to understand participants' comments but potentially may have introduced professional bias. Field notes, a reflective diary and discussion of bias were used to minimise these effects<sup>(40)</sup>.

In spite of these limitations, the findings from this study could be developed by a wider investigation of the predominant outcome preferences in a bigger and more diverse population and, if possible, to map these to demographic and clinical variables, for example, age and time since diagnosis. Future investigations are also needed from the perspective of practitioners, dietetic managers and those commissioning dietetic services to identify not only preferred outcomes but also the best way to evaluate them to determine the efficacy of dietetic intervention. For example, knowledge can be assessed before and after consultations and a number of validated tools exist to do this<sup>(33,41)</sup>. However, this alone is insufficient to assess empowerment to follow a gluten-free diet so a more sophisticated approach may be needed<sup>(42)</sup>.

In conclusion, this qualitative study aimed to explore the preferences for diet and nutrition-related outcome measures in adults with coeliac disease and adult carers of children with coeliac disease. The main themes identified were the knowledge and information they received, their satisfaction with the consultation, concerns about their short- and long-term health and, to a lesser extent, clinical monitoring. Preferences varied between patients and with length of time since diagnosis with coeliac disease.

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**Table 1**

Main themes and sub-themes described by participants as their preferred diet and nutrition-related outcomes

Knowledge and information		Satisfaction with the consultation	Concerns about health	Clinical monitoring
<p><i>Food</i></p> <p>Accurate information on which foods to eat / not eat Relevant to individual Oats Combining with other dietary restrictions, e.g. diabetes, lactose-free, allergies, vegetarian, cultural food choice</p> <p><i>Gluten-free foods</i></p> <p>Prescription entitlement Limits of prescription flexibility Local allowances HC2 certificate for payment Concern over high sugar or fat content or 'chemicals'</p> <p><i>Practical issues</i></p> <p>Cooking meals Suitable snacks Local information about shops Reading food labels Contamination Eating out, general and local Medication containing gluten Affordability Recipes</p>	<p><i>Nutrition</i></p> <p>Good dietary sources of calcium, iron and fibre on gluten-free diet Prescribed vitamins and minerals Healthy eating including reducing fat and sugar intake Portion sizes Weight gain including desirable and unwanted gain Relevance to life stage</p> <p><i>Resources</i></p> <p>Printed diet sheets Request cards for gluten-free products Direction to other suitable resources</p> <p><i>Condition</i></p> <p>Long-term consequences of adhering to gluten-free diet Sensitivity to gluten Explanation of medical and blood tests Genetic implications</p>	<p><i>Dietitian</i></p> <p>Positive attributes including experience of coeliac disease Negative attributes including lack of knowledge Provision of trustworthy knowledge Inspiring confidence Providing reassurance Personalised, flexible approach Consistency of dietitian</p> <p><i>Appointments</i></p> <p>Waiting time between diagnosis and appointment Follow up via email or telephone</p> <p><i>Effective communication with others</i></p> <p>General practitioner Consultant gastroenterologist Directing to Coeliac UK, allergy fair, peer support groups, suitable websites</p>	<p><i>Short-term relief from symptoms</i></p> <p>Improvement in tiredness and greater 'energy levels' Reduced diarrhoea, constipation, abdominal pain, bloating Reversal of undesirable weight loss Reduced neurological symptoms including 'brain fuzz', migraines Cessation of hair loss Improvement in general health</p> <p><i>Long-term</i></p> <p>Avoid osteoporosis Prevent long-term damage to villi and risk of bowel cancer Reduce anaemia Maintain healthy weight</p>	<p><i>Diet diaries</i></p> <p>Monitoring adequacy of nutritional intake</p> <p><i>Blood tests</i></p> <p>Tissue transglutaminase Ferritin, iron Vitamin D Folic acid Vitamin B<sub>12</sub></p> <p><i>DEXA scans</i></p> <p><i>Endoscopy</i></p>