









Coeliac UK's Research Conference 2016

Diagnosis and management of coeliac disease; time for reflection Thursday 10 March 2016



Diagnosis and management of coeliac disease; time for reflection

Royal College of Physicians 11 St Andrew's Place, Regent's Park, London, NW1 4LE

Chaired by Professor David Sanders Royal Hallamshire Hospital, Sheffield

- 10.00 Arrival and networking refreshments
- Coeliac UK welcome CEO Sarah Sleet
- 10.35 NICE guideline for coeliac disease research gaps Rachel Houten
- 10.55 Epidemiology of coeliac disease in the UK Dr Colin Crooks
- 11.15 Helping to diagnose coeliac disease in primary care Dr Geraint Preest
- Panel discussion 11.40
- 12.00 Lunch and networking









- Point of care tests in coeliac disease; new emerging evidence Dr Michelle Lau
- 13.20 Community pharmacy and coeliac disease Alastair Buxton
- 13.40 The Scottish Gluten-free Food Service Alpana Mair
- **Panel discussion**
- **Break refreshments** 14.25
- 14.45 Follow up in children with coeliac disease Dr Margreet Wessels.
- Dietitian led group coeliac disease clinics in compariosn to dietetic standard care in newly diagnosed patients **Nick Trott**
- 15.25 Management of patients with persistent symptoms Dr Matthew Kurien
- **Panel discussion**
- Chair's closing remarks
- 16.15 Close of meeting

This event has been kindly sponsored by Casillo Group, Cereal Partners Worldwide, ImmusanT, Provena, Thermo Fisher, Glutafin and Juvela.











Sarah SleetChief Executive, Coeliac UK

Welcome to the second day of Coeliac UK's Research Conference 2016. We hope this conference will provide you with a timely update and contribute to your ongoing professional development.

Today's programme reflects upon the work and research that supports or directly underpins the Charity's strategic aims around diagnosis and management of coeliac disease. We are committed to raising awareness of coeliac disease and to finding the estimated half a million people as yet undiagnosed with the condition. We want to cut the time it takes to achieve a diagnosis and to reduce misdiagnosis with IBS. Once diagnosed we want patients to have access to uniform high quality care and we promote the take up of innovative and efficient ways to deliver this care.

At this conference the research gaps will be highlighted and developments in detection of coeliac disease and managing the condition will be presented. There are panel discussions throughout the day and I hope you will participate and share your views and experiences.











Professor David Sanders Chair of Coeliac UK's Research Conference

Biography

Professor David S Sanders is a Professor of Gastroenterology and a Consultant Gastroenterologist at the Royal Hallamshire Hospital and the University of Sheffield. He has published >300 peer reviewed papers (H-score 45). He is internationally recognised for his work in coeliac disease, gastrostomy feeding and small bowel endoscopy. His other research interests include pancreatic exocrine insufficiency, irritable bowel syndrome and gastrointestinal bleeding. In 2010 he received a European Rising Star Award and the Cuthbertson Medal in 2011 (UK Nutrition Society). His clinical work with patients who have coeliac disease has resulted in him being awarded the Coeliac UK Healthcare Professional of the Year Award (2010) and the inaugural Complete Nutrition Coeliac Health Care Professional Award (2013). He is fortunate to work as part of the Sheffield Gastroenterology Team which has been recognised for their standards of care. The Small Bowel Endoscopy Service won one of the inaugural British Society of Gastroenterology National GI Care awards (2011) and the Medipex award (2013). In 2012 the percutaneous endoscopic gastrostomy team won both Health Service Journal primary care and integrated clinical care awards. In 2014 the Hallamshire Gastroenterology team again won one of the SAGE (Shire Awards for Gastrointestinal Excellence) awards for their primary care and GI bleed unit services. Professor Sanders has chaired both the British Society of Gastroenterology (BSG) Small Bowel and Nutrition Section (2006-2012) and the BSG Audit Committee (2010-2013). He is the current Chair of the Coeliac UK Health Advisory Council and the President of the International Society for Study of Coeliac Disease.











Rachel Houten

Health Economist, Internal Clinical
Guidelines, National Institute for
Health and Care Excellence

Biography

Rachel studied Economics as an undergraduate at Liverpool University and then spent a couple of years in operational research for a retail company. A change in focus meant studying for a postgraduate degree in Economics & Health Economics at the University of Sheffield. Her first job as a health economist was in academia, producing economic evaluations alongside clinical trials, and conducting primary research in areas where traditional economic methodology is challenging.

Rachel joined the Internal Clinical Guidelines team at NICE in April 2013. As part of the development team for the coeliac disease guideline her role was to systematically review the economic literature and develop economic analysis for consideration by the Guideline Committee in their decision making.

NICE guideline for coeliac disease - research gaps

Abstract

The presentation will look at how clinical guidelines are developed at NICE with a focus on the evidence available, and how the recommendations were formulated for coeliac disease.

The main focus of the economic analysis for coeliac disease was on diagnosis, therefore the presentation will explain how the economic model was developed, how it incorporated relevant clinical evidence, and how the analysis produced helped to formulate recommendations for national practice.

There will be a discussion on post diagnosis care and where, in the absence of evidence, the Guideline Committee made recommendations based on their opinions as experts.

The guideline development process also identified a number of research gaps for which new evidence could help to maximise diagnostic accuracy and improve the care of people with coeliac disease.



















Dr Colin Crooks

Academic Clinical Assistant Professor,
School of Medicine,
University of Nottingham

Biography

Dr Colin Crooks has been supported in his research training under Drs Joe West and Tim Card by a Medical Research Council Population Health Scientist Fellowship and Medical Research Council Centenary award. He successfully completed his PhD in epidemiology in 2013. He was a Specialty Registrar in Gastroenterology and General Internal Medicine, at the Royal Derby Hospital, 2014 - 2015 and he is presently an Academic Clinical Assistant Professor, School of Medicine, University of Nottingham. As part of his current research he is working on the Coeliac UK funded project using routine data to measure the occurrence of coeliac disease and dermatitis herpetiformis in the UK.

Epidemiology of coeliac disease in the UK

Abstract

It is estimated from screening studies that 1% of the UK population has coeliac disease and there is evidence, usually via serology, of undetected coeliac disease. The research team at Nottingham has explored the number of diagnoses of the condition in clinical practice in the UK. This has been achieved by looking at electronic healthcare records of people with coeliac disease and dermatitis herpetiformis, in both adults and children. This presentation will provide an overview of the current epidemiology of coeliac disease related to its occurrence and complications. The findings suggest that mechanisms to improve diagnostic pathways are needed to lead to better outcomes for people with, as yet, undiagnosed coeliac disease.



















Dr Geraint PreestGeneral Practitioner, South Wales

Biography

Geraint is a General Practitioner, practising as a family doctor in two communities in south Wales for the past 20 years. He has 15 years' experience of guiding the development of exciting and innovative projects aimed at providing education for a global audience of healthcare professionals utilising the latest information technology. Geraint has worked directly with Local Health Boards, Clinical Commissioning Groups, national organisations and professional bodies to provide educational material and testing for doctors with the aim of promoting good practice and better patient care, utilising his experience as an active frontline clinician. Geraint is also an author and presenter for the BMJ's online minor surgery training videos for doctors. Prior to his involvement with On Examination, he developed and authored one of the very first GP training websites in the UK and won a national award for pioneering the development of his practice website and online prescription ordering, ahead of the commercial providers. Geraint is particularly interested in looking at how innovation outside the field of medicine can be adapted to support frontline clinicians and improve patient care. He is a Member of Coeliac UK's Health Advisory Council and is married with four children, one of whom has coeliac disease.









Helping to diagnose coeliac disease in primary care

Abstract

Diagnosing coeliac disease in the primary care setting is tricky. Patients are presenting with ever more complex chronic diseases and consultation times are short. This presentation tells you about a new software tool that has been developed to work in conjunction with GPs' clinical systems to alert clinicians about patients who may have a high probability of coeliac disease based upon comorbidity and past medical history. This software will be rolled out to every GP practice in Wales during 2016 via NHS Wales Informatics Service. During this talk Dr Preest will explain how the software came to fruition and how it will hopefully increase the rates of diagnosis of coeliac disease in Wales during 2016/17.











Dr Michelle LauClinical Research Fellow,
Royal Hallamshire Hospital, Sheffield

Biography

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Dr Michelle Lau studied medicine at the University of Sheffield and qualified in 2009. She completed her housemanship in London and entered gastroenterology specialty training in Yorkshire, 2013. She is currently a clinical research fellow under the supervision of Professor David Sanders, Sheffield, working towards an MD on assessing the role of a point of care test in the diagnosis and management of coeliac disease. Her research focuses on the use of a novel point of care test, Simtomax®, in the pharmacy and endoscopy settings, with the evaluation of its sensitivities in detecting coeliac disease in a variety of clinical presentations and predicting remission in the management of coeliac disease. Her research also encompasses the acceptability and cost effectiveness of the point of care test.

Point of care tests in coeliac disease; new emerging evidence Abstract

Coeliac disease is estimated to affect 1 in 100 in the general population. The incidence of coeliac disease has increased over the last two decades, due to the increasing awareness of the condition and case finding strategies, as well as improved serological performance and endoscopic technology. Despite this, 75% patients still remain undiagnosed, causing significant health and economic burden. Our previous study showed that the mean delay in diagnosis in the Sheffield cohort was 4.9 years (range 0.25 - 16 years) and this was consistent









with the international literature. 13.6% patients had missed opportunities to be diagnosed, where they had a previous gastroscopy without duodenal biopsy within five years of diagnosis. More needs to be done to increase the detection of coeliac disease.

Several point of care tests (POCTs) for coeliac disease have been developed since 2000. The use of POCTs has not yet gained widespread use in the UK due to the inferior sensitivities compared to conventional coeliac serology from early studies. However, our recent head to head study of 3 commercially available POCTs (Biocard®, Biohit® and Simtomax®) showed that the novel POCT, Simtomax®, had the highest sensitivity, which was comparable to that of tissue transglutaminase antibodies. Dr Lau's MD explores the role of Simtomax in increasing the detection of coeliac disease in primary and secondary care and the management of the condition.

Dr Lau is currently conducting studies on the sensitivities of Simtomax® in the endoscopy setting for different clinical presentations of coeliac disease: detecting coeliac disease in patients presenting with general gastrointestinal symptoms, and in patients with iron deficiency; predicting histological remission in patients with coeliac disease who are on a gluten-free diet; and differentiating between coeliac disease and non coeliac gluten sensitivity. The sensitivities of Simtomax® are compared to tissue transglutaminase antibodies and endomysial antibodies based on the gold standard of duodenal histology.

The latest available results of the above ongoing studies, as well as the cost saving economic model using Simtomax®, will be presented. Dr Lau is also about to start conducting a case finding feasibility study on utilising Simtomax® in community pharmacies, which she is excited to share with you.











Alastair Buxton
Director of NHS Services, Pharmacy
Services Negotiating Committee

Biography

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Alastair joined the PSNC in November 2002 as Head of NHS Services, with responsibility for policy on national community pharmacy services. In May 2015 he became Director of NHS Services, leading a team covering policy and support on locally and nationally commissioned community pharmacy services, monitoring of the wider NHS and healthcare policy environment and community pharmacy and internal PSNC IT. Alastair is a member of PSNC's negotiating team and regularly works with colleagues at NHS England and the Department of Health on matters relating to his policy responsibilities. Alastair qualified as a pharmacist in 1994 and worked in community pharmacies in Shropshire for 8 years. In 2012 Alastair was designated a Fellow of the Royal Pharmaceutical Society for distinction in the pharmacy profession.

Community pharmacy and coeliac disease

Abstract

This presentation will provide an introduction to community pharmacy and the wide range of services which are provided by pharmacy teams.

There is an estimated 500,000 people in the UK who remain undiagnosed with coeliac disease. The reason for under diagnosis in coeliac disease may be due to a range of challenges, including lack of awareness of the condition and misdiagnosis, since it is established that one in four people diagnosed with coeliac disease have previously been treated for irritable bowel syndrome. Also the symptoms of coeliac disease are similar to the symptoms of many minor gastro problems which people may prefer to discuss with their local pharmacist rather than their GPs.

A project commissioned by Coeliac UK and supported by the NAPC explored the early recognition of coeliac disease in community pharmacies and will be described.

The opportunities, benefits and barriers to using community pharmacy in recognition and management of coeliac disease will be examined, particularly in the context of the current NHS England commissioning environment.



















Alpana Mair
Deputy Chief Pharmaceutical
Officer, Scottish Government

Biography

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Alpana currently works as Deputy Chief Pharmaceutical Officer for the Scottish Government. Responsibilities include policy on delivery of Prescription for Excellence and pharmaceutical care in all healthcare settings, and advising Ministers on pharmaceutical matters. She has over 20 years' experience as a prescribing adviser and also works as an independent prescriber in Primary care running clinics to manage patients with long term conditions such as diabetes, respiratory, cardiovascular and for patients with drug misuse.

She chairs the national group that produced National guidance for addressing polypharmacy, working to get this implemented as part of the core Scottish GP contract in a multidisciplinary approach and the Royal Pharmaceutical Society report on Pharmaceutical care in Care homes. Alpana coordinates a subgroup as part of the European Union work on Active and Healthy Aging on polypharmacy and medications adherence. Alpana is leading a consortium across Europe for European health call project currently looking at the delivery of polypharmacy.

She has led long term conditions projects supporting patients with their medicines across health and social care in Lothian and also in NHS Lothian, developed a framework whereby polypharmacy can be delivered by pharmacists and GPs.

Alpana is an honorary lecturer at Strathclyde University, honorary senior lecturer at Robert Gordon University and teaches on the non medical prescribing course at Napier University.

The Scottish Gluten-free Food Service

Abstract

The Scottish Gluten-free Food Service (GFFS) is an NHS Scotland service available through local pharmacy that allows the ordering and receipt of gluten-free food without the need to go through the GP. It provides patient centred guidance and the service is available to patients with a confirmed diagnosis of coeliac disease or dermatitis herpetiformis, living in Scotland and registered with a GP practice. Adults with coeliac disease are also able to have an annual health check at the pharmacy to help monitor their condition.

The GFFS was piloted between April 2014 and March 2015 and in the autumn 2015 the Scottish Government announced the GFFS would become a permanent aspect of the community pharmacy contract. This presentation will provide an overview of the service.



















Dr Margreet WesselsPaediatric Gastroenterologist,
Rijnstate Hospital, Arnhem, the
Netherlands.

Biography

Margreet Wessels trained as a paediatric gastroenterologist at the Leiden University Medical Center (LUMC) and the Erasmus University Medical Center, Rotterdam, both in the Netherlands. She started her PhD in 2010 with supervisor Luisa Mearin, a paediatric gastroenterologist with a special interest in coeliac disease. Her PhD is entitled "Innovation in care for children with coeliac disease" and is still in progress. Currently, she works as a paediatric gastroenterologist at the Rijnstate Hospital in Arnhem, the Netherlands.

Follow up of coeliac disease in children

Abstract

Objectives - To determine the frequency of nutritional deficiencies and thyroid dysfunction in children with coeliac disease (CD) at diagnosis and during follow up after initiation of a gluten-free diet, since laboratory investigations of haemoglobin, ferritin, calcium, folate, vitamin B12, vitamin D and thyroid function are regularly ordered in CD children despite insufficient evidence for their need.

Methods - Between 2009 and 2014, test results of haemoglobin, ferritin, folate, vitamin B12, calcium, vitamin D-25-OH, FT4 and TSH of CD children regularly seen at the Leiden University Medical Center were investigated. Laboratory reference ranges were used to define abnormal results. Pearson's chi-square test for trend, unpaired t-test and one-way ANOVA were used for statistical analysis.

Results - 182 children were evaluated, wherein 119 were new diagnoses. On average, 17% of results per year were missing due to incomplete blood investigations. Iron deficiency (28%) and iron deficiency anaemia (9%) were found upon CD diagnosis. Folate (14%), vitamin B12 (1%) and vitamin D deficiencies (27%) were also seen. No hypocalcemia or thyroid dysfunction was found. At follow up, iron deficiency, iron deficiency anaemia, folate and vitamin D deficiency were respectively observed in 8%, 2%, 3% and 25% of patients. No vitamin B12 deficiency, hypocalcemia or thyroid disease was found.

Conclusion - Complementary blood investigations are relevant at time of CD diagnosis but have little diagnostic yield during follow up visits once the patient is placed on a gluten-free diet. Thus, we recommend that these variables only be assessed on indication, such as fatigue or abnormal growth.



















Nick Trott RDRegistered Dietitian, Royal
Hallamshire Hospital, Sheffield

Biography

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Nick studied at the University of Wales Institute, Cardiff where he obtained an Honours degree in Nutrition and Dietetics. Post graduate training, Nick has worked in a variety of clinical areas within the NHS including Critical Care, Oncology and Haematology. Currently Nick works as a Gastroenterology Dietitian, covering the specialist coeliac clinic at the Royal Hallamshire Hospital Sheffield. His areas of particular clinical interest include coeliac disease, gluten ataxia, non coeliac gluten sensitivity and the FODMAPs approach to functional bowels disorders. He is presently completing a post graduate master's degree examining the efficacy of group education in coeliac disease.

Group dietetic clinics vs individual appointments

Abstract

There has been a fourfold increase in the rate of diagnosed cases of coeliac disease in the UK over the past two decades. This exponential rise in new cases will pose continuity of care and service delivery problems for the National Health Service. A gluten-free diet is the cornerstone of treatment for patients diagnosed with coeliac disease and dietetic input is one of the factors shown to support adherence. However, there is a wide variation in provision of dietary consultation services for patients diagnosed with coeliac disease.

Given the likely increase in need for dietetic consultations in the coeliac population, one potentially cost effective option could be dietetic led coeliac group clinics.

From previous research in patient cohorts receiving treatment for diabetes and obesity, it has been demonstrated that a group clinic approach can deliver the education needs of these client groups, with the additional benefit of providing peer support.

This presentation discusses the development of a dietetic led Coeliac Group Clinic (CGC) for newly diagnosed patients. This approach is compared to standard dietetic care, of one to one clinics, in relation to patient adherence at first follow up, quality of life measures and overall cost effectiveness.



















Dr Matthew KurienNIHR Academic Clinical
Lecturer, University of Sheffield

Biography

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Dr Matthew Kurien is an NIHR Academic Clinical Lecturer at the University of Sheffield and a specialty registrar on the South Yorkshire rotation. He has an interest in small bowel disease and nutrition. He qualified in 2003 and subsequently completed a postgraduate diploma in medical education at the University of Nottingham. In 2010 he was appointed as a Bardhan Research and Education Trust (BRET) clinical research fellow under the supervision of Professor David Sanders, which culminated in an MD from the University of Sheffield in 2014 for his work in gastrostomy feeding. His current research interests are in the area of coeliac disease, with the aim of improving detection and subsequent management.

Management of patients with persistent symptoms

Abstract

Most people with coeliac disease have a response to a gluten-free diet. This talk reviews the management of individuals who fail to get better on the diet, and highlights the differences between non responsive coeliac disease and refractory coeliac disease.

















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Coeliac UK's Healthcare Professional Membership

As a healthcare professional (HCP) or researcher with an interest in coeliac disease, you may wish to become a HCP Member of Coeliac UK. On joining, you will be able to access:

- early registration to the Coeliac UK Research Conference
- exclusive access to post Research Conference videos on our website
- our Electronic Food and Drink Directory, Gluten-free on the Move smartphone app, Recipe Database and Venue Guide
- hard copy of our Food and Drink Directory
- Crossed Grain magazine
- monthly electronic newsletter to support your patients with their condition and diet
- Professional eXG (quarterly electronic newsletter)
- your own personalised online Scrapbook where you can save all downloadable documents and bookmark the webpages that you find the most useful
- access to our online publications
- an online forum where you can share best practice and information with other HCP Members.

To join, go to www.coeliac.org.uk/join-us/hcp and complete the online form. Professional eXG is our quarterly electronic newsletter for HCPs, in each edition we have an article called 'People and Patients', written by HCPs to share best practice in the diagnosis and management of patients with coeliac disease. Recent articles have covered the management of patients with the dual diagnosis of coeliac disease and Type 1 diabetes and five top tips for providing follow up care to children with coeliac disease. If you are interested in writing for Professional eXG or would like to find out more we would love to hear from you, please contact Lorna at lorna.gardner@coeliac.org.uk









In 2016 we're asking: is it coeliac disease?

Coeliac UK will be continuing to focus on raising diagnosis rates for coeliac disease in 2016. We're looking for the estimated half a million people in the UK who are struggling with the ongoing symptoms and long term health risks of undiagnosed coeliac disease and dermatitis herpetiformis.

We want these people to ask themselves: is it coeliac disease?

Launched last year, our campaign highlights some of the most common symptoms of coeliac disease crippling fatigue, bouts of diarrhoea, stomach pain, serious mouth ulcers, and invites those engaging with the campaign to take the first simple step towards diagnosis - completing the Coeliac UK online assessment¹. Around 35,000 people completed this initial step in 2015.

We'll be refreshing our campaign in 2016 to focus on the symptom of unexplained or recurring anaemia, a key symptom linked to malabsorption caused by the damage to the small intestine in people with coeliac disease.

To find out more, please go to: isitcoeliacdisease.org.uk



To find out more, please visit isitcoeliacdisease.org.uk

¹ Developed by Coeliac UK based on NICE Guidance for the recognition, assessment and management of coeliac disease









Healthcare professionals can also ask: is it coeliac disease?

If you're a healthcare professional and would like to join our campaign to find the estimated half a million people living in the UK with undiagnosed coeliac disease, there is plenty that you can do to help.

Screen IBS patients for coeliac disease

Around a quarter of those diagnosed with coeliac disease had previously been treated for irritable bowel syndrome (IBS). We believe that targeting IBS patients is a good way to improve diagnosis, and recommend screening clinics. NICE Guidance recommends screening for coeliac disease prior to an IBS diagnosis.

Offer testing for coeliac disease to patients with unexplained or recurrent anaemia

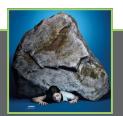
Research reports that iron deficiency anaemia occurs at coeliac disease diagnosis in 30 - 50% of patients and vitamin B12 or folate deficiency is also common.

NICE guidance recommends offering testing for coeliac disease to anyone with unexplained iron, vitamin B12 or folate deficiency.

Update your knowledge

If it's been a while since you refreshed your knowledge of coeliac disease, or this is a new area of work for you, you can access a range of information and training tools at www.isitcoeliacdisesase.org.uk/healthcare-professional-resources
Coeliac UK has produced a range of posters and an information leaflet for patients wanting to know more about coeliac disease, its symptoms and the diagnosis process. You can view all of the materials, including videos at www.isitcoeliacdisease.org.uk/view-the-campaign

And, you can order printed materials for your workplace at the following address www.isitcoeliacdisease.org.uk/supporter-resources









Coeliac UK's Research Fund

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Coeliac UK is committed to commissioning and funding the highest quality research into coeliac disease (CD) and dermatitis herpetiformis (DH). Only by increasing the knowledge base around the condition can the long term vision of a world without CD be achieved.

Since 2005 we have contributed nearly £2M to research projects across a range of fields of interest. To coincide with the review of our Research Strategy, later this year, and in the lead up to our 50th anniversary in 2018, we are driving a step change in the scale and ambition of our research programme. As part of this step change, we are developing a dedicated research fund to support the dreams and aspirations of patients and carers, clinicians and scientists alike for research into CD. We want to build a critical mass for future support of research and to encourage and inspire a new generation of researchers.

As well as commissioning and funding the very best research projects, we will build capacity in research into CD and DH, where there is currently a deficit, by encouraging the best candidates to embark on an early career in CD and DH; developing the joint funding of fellowships with the Medical Research Council.

Our funded projects will fill critical gaps in our knowledge and understanding of the condition, while addressing the shared priorities across the CD community.

To do this, we need to raise more money, specifically for research, to help realise the dreams and ambitions of patients and carers, clinicians and researchers today and in the future.

Find out more by visiting www.coeliac.org.uk/Researchfund

Please use these pages for any notes you'd like to take

















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'Diagnosis and management of coeliac disease; time for reflection' has been approved by the Federation of the Royal Colleges of Physicians of the United Kingdom for 4 category (1 external) CPD credits

The Coeliac UK 2016 Research Conference is endorsed by:



BDA endorsement applies only to the educational content of the learning activity



The Primary Care Society of Gastroenterology's Spring meeting takes place 22 April in London.

For more information visit www.pcsg.org.uk/events

Visit www.coeliac.org.uk/research for more information on Coeliac UK's:

- Research Strategy
- funding opportunities
- previous Research Conference videos
- funded research.



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