

This is a repository copy of *Prescribing gluten-free foods in general practice*.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/134776/

Version: Accepted Version

Article:

Kurien, M. orcid.org/0000-0002-4227-9500, Trott, N., Sleet, S. et al. (1 more author) (2018) Prescribing gluten-free foods in general practice. British Journal of General Practice, 68 (673). pp. 364-365. ISSN 0960-1643

https://doi.org/10.3399/bjgp18X698045

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



BJGP - Invited Editorial

Prescribing gluten free foods in General practice

Matthew Kurien, Senior Clinical Lecturer and Honorary Consultant Gastroenterologist^{1,2}

Nick Trott, Specialist Gastroenterology Dietitian¹

Sarah Sleet, Chief Executive of Coeliac UK³

David S Sanders, Professor of Gastroenterology and NHS Consultant^{1,2}

¹Academic Unit of Gastroenterology, Departments of Infection and Immunity and

Cardiovascular Science, University of Sheffield, Medical School, Beech Hill Road, Sheffield,

South Yorkshire, S10 2RX

²Department of Gastroenterology, Royal Hallamshire Hospital, Sheffield Teaching Hospitals

NHS Foundation Trust, Glossop Road, Sheffield, S10 2JF

³Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Bucks, HP11 2QW

Word Count: 1198

References: 10

Correspondence:

Professor David S Sanders, Room P39, Department of Gastroenterology, Royal Hallamshire

Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Glossop Road, Sheffield, S10

2JF

Email: david.sanders@sth.nhs.uk

Telephone Number: 0114 2261179

Fax Number: 0114 2712692

The Department of Health and Social Care has recently published their consultation outcome regarding the availability of gluten-free foods (GFF) on NHS prescriptions. Following an unprecedented number of responses from patients, healthcare professionals and professional bodies, the Government has decided to continue to provide GFF on prescription but restrict the products available to breads and mixes. This favoured option by the majority of consultation respondents has now proceeded to formal ratification, through an amendment to the National Health Service Regulations 2004, Schedule 1. In this editorial, we discuss the controversies that have existed regarding prescription of GFF in coeliac disease where the gluten free diet is the treatment, and discuss the future implications that this decision may have on both patients and the NHS.

The history of GFF Prescriptions

GFF products have been available in the UK via prescription for those medically diagnosed with coeliac disease for over 50 years, with the aim of supporting dietary adherence and reducing complications. In recent years, these prescriptions were restricted to staple foods, approved by the Advisory Committee on Borderline Substances (ACBS). The National Prescribing Guidelines endorsed by both the Primary Care Society for Gastroenterology and the British Dietetic Association set out recommendations to healthcare professionals on the quantity of gluten-free staple foods that may be prescribed.² These allowances (in units) were determined by an individual's age and sex (e.g. male 19-59 years = 18 units, female 19 - 74 years = 14 units) and based upon: a) continued consumption of naturally gluten-free foods (e.g. potato and rice), b) data from the National Diet and Nutrition Surveys and c) the Eatwell Guide for balanced eating.²

These guidelines, first launched in 2004 offer equitable allowances for all UK patients, however costs to individuals vary. In England people with coeliac disease pay prescription charges (unless they meet exemption criteria), whilst prescriptions in Scotland, Northern Ireland and Wales are free. This method of support differs to some other countries where government subsidies (e.g. Italy, Argentina) or tax deductibility of excess costs (e.g. USA, Canada) are being used.³⁴

Recent controversies in GFF Prescriptions and Fake News

In 2014 NHS PrescQIPP raised concerns that the annual cost of prescriptions for GFF products in England was £24.7 million.⁵ Recommendations were made to restrict prescriptions to 8 units

of bread and flour only, with the ambition of saving potentially £10 million.⁵ This started a trend for restricting access to GFF on prescription by a number of clinical commissioning groups (CCGs). A geographical variation in care subsequently developed within England, that differed to NHS practices in Scotland, Northern Ireland and Wales where National Prescribing Guidelines are still followed.

These local decisions and concerns about the variation in GF prescribing policies were widely discussed in both the medical literature and the national press. These included concerns about the cost of GFF products, NHS procurement practices and the appropriate use of a general practitioner's time in prescribing GFF products. In relation to costs the Daily Mail ran a front-page headline on the 17th August 2015 deriding a £116 million spend on gluten free junk food on prescription. This article fuelled further misconceptions about GFF prescriptions and was later retracted due to significant factual inaccuracies (true spend - £26.8 million on staple food items only).

What was the Department of Health & Social Care consultation?

A national public consultation was conducted by the Department of Health & Social Care between the 31st March and the 22nd June 2017. The consultation suggested that the spend of £26.6 million on GFF prescriptions could be redeployed into other areas of the NHS. The NHS was unable to enforce restrictions to GFF prescriptions as they lacked statutory authority to do so, with prescribing responsibilities laid down in national prescribing legislation that only Government could amend., where Views on three options were sought: 1) make no changes to GFF prescribing 2) end all GFF prescribing in primary care by adding GFF products to Schedule I and 3) restrict to selected GFF products (namely bread and mixes) on prescription.

Holding a national consultation on the issue was supported by both NHS England and clinical commissioners. Lauren Hughes, Director of Clinical Policy and Operations, NHS England stated: "The purpose of this review is to develop guidance at a national level that will support CCGs locally to manage their resources and reduce the differing approaches and regional variation in prescribing across England. Julie Wood, Chief Executive, NHS Clinical Commissioners said in March 2017: "Having national support from NHS England and the DH (Department of Health) for those local decisions means there will be more consistency and reduce variation for patients."

The health minister's preference following the consultation was to continue GFF on prescription but restrict products to breads and flour mixes. Key themes considered included accessibility and availability of GFF, cost of GFF, impact on adherence to a gluten-free diet, appropriate use of NHS resources, health inequalities, consequences of untreated coeliac disease and the potential for system abuse and wastage. The evidence was considered alongside the views of key stakeholders including clinicians, commissioners and patients.

The immediate response to the government's decision on GFF prescribing has been mixed. Coeliac UK has welcomed the decision of a national approach to the availability of GFF on prescription, whilst a statement from the NHS Clinical Commissioners believes a missed opportunity has occurred to release entire GFF spending funds to other frontline NHS services. Although regulations will be put in place to restrict the type of product that can be prescribed, Clinical Commissioning Groups will still be able to develop local policies that restrict prescribing further. Thus the current scenario of a postcode lottery where some patients are able to access prescriptions in line with the national approach while others have effectively no access may continue.

Consequences to patients and the NHS

The long-term sequelae of restricting GFF prescriptions may take many years to reveal themselves with regards to patient outcomes. Adherence to a gluten free diet is recognised to be difficult for people with coeliac disease, varying between 42-91%, and influenced by access to GFF prescriptions.⁸ A previous NICE health economic analysis estimated that the cost of prescribing GFF was £194.24 per patient. This figure represented a low treatment cost for a lifelong autoimmune disease, which contrasted treatment costs associated with long term complications such as osteoporosis, where an average fracture cost was £27,000.⁸ Unless the newly set out national policy is reflected across England patients may be at risk of long term complications. Only time will tell whether this concern will come to fruition.

Importantly, it should be recognised that this prescription debate has raised the profile of coeliac disease - a lifelong condition affecting 1% of the UK population. The average delay in diagnosis is 13 years, with individuals reporting on average 13 consultations with their General Practitioner prior to a diagnosis being established. In the United Kingdom, three out of four cases of coeliac disease remain unrecognised. Medical nihilism has for too long negatively influenced the outcomes of people with coeliac disease. Hopefully, through continued working

between commissioning groups, patients, stakeholders and clinicians, an optimal use of available resources will be achieved, ensuring enhanced outcomes for these patients.

References:

- 1. Department of Health and Social Care (2018) Availability of gluten-free foods on NHS prescription. https://www.gov.uk/government/consultations/availability-of-gluten-free-foods-on-nhs-prescription. (accessed 15 Feb 2018)
- Gluten-free foods: a revised prescribing guide 2011. Produced in collaboration with the British Dietetic Association, the Primary Care Society for Gastroenterology and Coeliac UK, 2011. https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/. (accessed 15 Feb 2018)
- 3. See JA, Kaukinen K, Makharia GK, et al. Practical insights into gluten-free diets. Nat Rev Gastroenterol Hepatol 2015;12(10):580-91.
- 4. Pinto-Sanchez MI, Verdu EF, Gordillo MC, et al. Tax-deductible provisions for gluten-free diet in Canada compared with systems for gluten-free diet coverage available in various countries. Can J Gastroenterol Hepatol 2015;29(2):104-10.
- 5. NHS PrescQIPP (2015) Bulletin 69. NHS PrescQIPP Guidance on the prescribing of gluten-free foods.
- 6. Kurien M, Sleet S, Sanders DS, et al. Should gluten-free foods be available on prescription? BMJ 2017;356:i6810. doi: 10.1136/bmj.i6810
- 7. Daily Mail (2015) Clarifications and corrections: Food on prescription.

 http://www.dailymail.co.uk/home/article-3326264/Clarifications-corrections-Food-prescription.html. (accessed 15 Feb 2018)
- 8. Coeliac UK (2018) Department of Health consultation response.

 https://www.coeliac.org.uk/document-library/4509-department-of-health-consultation-response/?return=/campaigns-and-research/campaigning-on-health/national-campaign-to-protect-gluten-free-prescribing-in-england/">https://www.coeliac.org.uk/document-library/4509-department-of-health-consultation-response/?return=/campaigns-and-research/campaigning-on-health/national-campaign-to-protect-gluten-free-prescribing-in-england/
 Feb 2018)
- 9. NHS Clinical Commisioner (2018) NHSCC statement on the result of the Department of Health and Social Care consultation on the availability of gluten-free foods on NHS prescriptions. https://www.nhscc.org/latest-news/nhscc-statement-on-the-result-of-the-department-of-health-and-social-care-consultation-on-the-availability-of-gluten-free-foods-on-nhs-prescription/ (accessed 15 Feb 2018)

10. Gray AM, Papanicolas IN. Impact of symptoms on quality of life before and after diagnosis of coeliac disease: results from a UK population survey. BMC Health Serv Res 2010;10:105.