registration purposes. The development of this type of outcome measurement requests close collaboration with patient organisations, preferable in multinational setting. We hope that the data from our study and the eloquent editorial by our Spanish colleagues may contribute to development of such patient reported outcome measures.

ACKNOWLEDGEMENT

The authors' declarations of personal and financial interests are unchanged from those in the original article.[1]

ORCID

P. F. Vollebregt http://orcid.org/0000-0002-3158-6652

LINKED CONTENT

This article is linked to Vollebregt et al and Cañete and Domènech papers. To view these articles visit https://doi.org/10.1111/apt.14599 and https://doi.org/10.1111/apt.14637.

P. F. Vollebregt[1]
A. A. van Bodegraven[1,2]
T. M. L. Markus-de Kwaadsteniet[3]
D. van der Horst[3]
R. J. F. Felt-Bersma[1]
[1]*Department of Gastroenterology and Hepatology, VU University Medical Centre, Amsterdam, The Netherlands*
[2]*Department of Gastroenterology and Hepatology, Zuyderland Medical Center, Limburg, The Netherlands*
[3]*CCUVN, Breukelen, The Netherlands*
Email: p.vollebregt@vumc.nl

REFERENCES

1. Vollebregt PF, van Bodegraven AA, Markus-de Kwaadsteniet TML, van der Horst D, Felt-Bersma RJF. Impacts of perianal disease and faecal incontinence on quality of life and employment in 1092 patients with inflammatory bowel disease. *Aliment Pharmacol Ther*. 2018;47:1253-1260.
2. Cañete F, Domènech E. Editorial: faecal incontinence—the hidden burden of inflammatory bowel diseases. *Aliment Pharmacol Ther*. 2018;47:1715-1716.
3. Mahadev S, Young JM, Selby W, et al. Quality of life in perianal Crohn's disease: what do patients consider important? *Dis Colon Rectum*. 2011;54:579-585.
4. Schwartz DA, Herdman CR. Review article: the medical treatment of Crohn's perianal fistulas. *Aliment Pharmacol Ther*. 2004;19:953-967.
5. Lam TJ, van Bodegraven AA, Felt-Bersma RJF. Anorectal complications and function in patients suffering from inflammatory bowel disease: a series of patients with long-term follow-up. *Int J Colorectal Dis*. 2014;29:923-929.

DOI: 10.1111/apt.14670

Editorial: finding the coeliacs – should everyone be screened?

In the field of coeliac disease, there are matters that are certain, matters that are uncertain and matters that are frankly unknown. It is certain that coeliac disease can be a significant source of morbidity and that a large proportion of patients are undiagnosed, though this appears to be improving.[1] There is less certainty about whether undiagnosed, untreated coeliac disease is associated with increased risk of mortality, as studies offer conflicting results.[2] In the category of unknowns is this basic question: which patients should be tested for coeliac disease?

Screening the general population has not been favoured due to (1) the uncertain natural history of long-term asymptomatic undiagnosed coeliac disease; (2) the imperfect specificities of serologies, which would likely yield a large number of false positives when testing a population for a disease with a prevalence of <1%; and, most importantly, (3) a lack of a prospective, controlled study testing any screening strategy with regard to improvement in patient outcomes. Instead of screening, a case-finding approach has been advocated, but the evidence for this alternative approach has been relatively lacking. It is this void that the study by Hujoel et al addresses.[3]

The investigators performed a nested case-control study, comparing patients with undiagnosed coeliac disease to matched controls, measuring for indications that would warrant coeliac disease testing. Of concern, chronic diarrhoea was less common in coeliac disease? This was likely due to left-censoring, as patients who were already diagnosed with coeliac disease prior to serum collection were excluded. Thus, it is possible that patients with chronic diarrhoea or irritable bowel syndrome were tested for and diagnosed with coeliac disease long before serum collection and the paradoxical low prevalence of these symptoms in undiagnosed individuals is due to exclusion of such symptomatic patients. Moreover, under-ascertainment of indications may have occurred in the medical record review, as acknowledged by the authors. For example, heartburn was noted in only 1.5%-1.8% and irritable bowel syndrome in 2%-4.5% of the population.

Nevertheless, the study by Hujoel et al offers sobering news about this persistent unknown in coeliac disease. Case-finding has been the default, and there appear to be serious problems with this approach. If identifying the approximately 1% of individuals with coeliac disease is akin to finding a needle in a haystack, it turns out that the needle and the hay are more similar with regard to their shape and texture than we originally thought. The authors rightly conclude that alternatives to case-finding should be considered. Now that the default option has been shown to be flawed, we should seize the opportunity to tackle this unanswered question of which patients should be tested for coeliac disease, and to determine definitively whether the answer is "Everyone." The project—a large, multicentre randomized trial of screening the general population for coeliac disease—would be ambitious but of great potential benefit.

ACKNOWLEDGEMENT

Declaration of personal interests: None.

FUNDING INFORMATION

None.

LINKED CONTENT

This article is linked to Hujoel et al paper. To view this article visit https://doi.org/10.1111/apt.14625.

B. Lebwohl
P. H. R. Green
Celiac Disease Center, Department of Medicine, Columbia University College of Physicians and Surgeons, New York, New York
Email: pg11@columbia.edu

REFERENCES

1. Choung RS, Unalp-Arida A, Ruhl CE, Brantner TL, Everhart JE, Murray JA. Less hidden celiac disease but increased gluten avoidance without a diagnosis in the United States: findings from the National Health and Nutrition Examination Surveys from 2009 to 2014. Mayo Clin Proc 2016.
2. Ludvigsson JF. Mortality and malignancy in celiac disease. *Gastrointest Endosc Clin N Am*. 2012;22:705-722.
3. Hujoel IA, Van Dyke CT, Brantner T, et al. Natural history and clinical detection of undiagnosed coeliac disease in a North American community. *Aliment Pharmacol Ther*. 2018;47:1358-1366.