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Characterisation of patients diagnosed with pernicious anaemia: A first step towards James Lind Alliance Priority Setting Partnership driven research

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Pernicious anaemia (PA) is characterised by vitamin B12 deficiency due to autoimmune-mediated loss of gastric parietal cells and intrinsic factor, a specific transporter for the intestinal uptake of vitamin B12. PA is typically managed with lifelong intramuscular hydroxocobalamin injections every 2-3 months. However, this regimen lacks robust scientific validation and fails to account for varied symptomatic responses among patients, with many requiring more frequent injections(1).

The Pernicious Anaemia Society (PAS) is a patient-driven charity that identified 10 research priorities for PA through a James-Lind Alliance Priority Setting Partnership(2). PAS members were surveyed to build a PA Research Repository, exploring diagnostics, treatment, family histories, and comorbidities. This project aims to better understand and manage the condition by addressing these priorities and characterising a cohort of patients.

An online survey was designed using SurveyMonkey comprising 21 questions to collect data on demographics, mode and timing of PA diagnosis, diagnosed comorbidities, family history of PA or other autoimmune conditions, and management (type, regime and patient satisfaction). All questions were compulsory. The survey was sent to 3,482 PAS members (April-September 2022) via the PAS newsletter, email, and website. Chi-square tests were used to investigate associations between gender and survey responses. The study protocol and procedures received a Favourable Ethical Opinion.

Completed surveys were received from 1,191 PAS members (34% response rate). Among these, 971 (81%) had a confirmed PA diagnoses, and the cohort was predominantly UK-based (92%) females (81%) aged 23-90 years, with a wide age of onset (10 to 80 years, mean 49 years). Diagnoses were typically based on low serum B12 (40%), positive intrinsic factor (31%), and/or parietal cell autoantibodies (13%), with 7% diagnosed via the now obsolete Schilling test. Diagnostic delays were common, 39% of participants reported waiting ≥3 years for a diagnosis. Over half (59%) reported other micronutrient deficiencies upon diagnosis. Half reported additional autoimmune diseases, with one-third having family with PA or other autoimmune conditions. Treatment primarily involved hydroxocobalamin intramuscular injections (77%), with 48% following the recommended guidelines and 52% injecting more frequently. Females had higher prevalence rates of Hashimoto's disease (27% vs 7%), asthma (33% vs 20%), and iron deficiency (49% vs 35%) (all $p < 0.05$).

This survey has established the first-ever PA research repository of over 1,000 participants offering initial insight into the complexities of PA, from varied age-of-onset and familial clustering to diagnostic challenges and treatment variability. These results support the need for improved diagnostic and treatment strategies, supporting the research recommendations made in the recent vitamin B12 deficiency NICE guidelines(3). It also highlights the potential of collaborative research with a patient-driven charity. Collaborative efforts aim to advance patient-centred PA research, improve treatment evaluation, and develop evidence-based approaches to managing this complex condition.

References

1. Hooper M, Hudson P, Porter F *et al.* (2014) *Br J Nurs* **23**(7), 376–381.
2. Staley K, Ahmadi KR *et al.* (2022) *BMJ Open* **12**(8), e065166.
3. National Institute for Health and Care Excellence (NICE) (2024) Vitamin B12 deficiency in over 16s: diagnosis and management [Available at: https://www.nice.org.uk/guidance/ng239].