

How Do Patients Receiving Prescribed B₁₂ Injections for the Treatment of PA Perceive Changes in Treatment During the COVID-19 Pandemic? A UK-Based Survey Study

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Abstract

Pernicious anemia (PA) is a chronic condition that is usually treated using B₁₂ injections. Due to the pandemic, many patients were prescribed an alternative oral B₁₂ treatment. There is limited evidence that this is effective at managing symptoms of PA. The aim of this study was to document treatment changes across the United Kingdom and the impact on patient experience. An online survey explored how the treatment of PA has been managed during the early stages of the pandemic; responses were analyzed for a subsample of participants receiving prescribed B₁₂ injections and where changes in treatment applied (n = 329) using content analysis. The most common reported change was the suspension of injections, with oral B₁₂ being offered as an alternative treatment. Patients were concerned about the long-term impact that changes would have on their condition management, and many stated that they were dissatisfied with the level of care received. Those who were supported by health care providers to continue their usual treatment reported experiencing improved health and well-being. This study highlights the major impact of treatment changes on patient health outcomes and the need to further support health care professionals with PA management during and beyond the pandemic.

Keywords

pernicious anemia, treatment change, patient experience, COVID-19, decision-making

Pernicious anemia (PA) is an autoimmune condition where the body fails to absorb vitamin B₁₂ (Cobalamin) in the intestine, which has serious implications for its sufferers. The prevalence of PA worldwide may range between 50 and 4000 cases per 100 000; however, this may vary due to the complexity of diagnosis (1). In the United Kingdom, it is estimated that PA incidence varies between 1 and 5 in 100 000 cases per year (2). Pernicious anemia is commonly treated by regular quarterly B₁₂ injections (hydroxocobalamin) which are administered in primary care. Due to Coronavirus disease 2019 (COVID-19), primary care services have adapted to reduce the number of face-to-face consultations. In recent weeks, many patients with PA have been moved to alternative treatments which use oral B₁₂ in tablet form. However, there is a debate that this oral replacement is not effective at managing PA where absorption and neurological manifestations may be an issue (3). Current guidance from the British Society for Hematology is to offer oral B₁₂

(cyanocobalamin) as a replacement treatment, however, where possible to continue treating using B₁₂ injections (4).

Recently, the Pernicious Anaemia Society, a nonprofit support group for individuals with PA, has been inundated with requests from individuals who are concerned about the long-term health consequences of being unable to receive their usual treatment (5). The type of treatment being offered is dependent on the provision within individual primary care

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settings. The extent to which PA treatment has been impacted in the United Kingdom is unknown. An online survey was designed to capture individual's experience of PA treatment change during the COVID-19 pandemic. Specific objectives of this study are to (1) establish the extent to which treatment for PA has changed across the United Kingdom, (2) to explore respondents' perceptions on how changes to treatment have been managed within their primary care setting, and (3) to document whether patients have made any changes to how they manage their PA.

Methods

The current study received ethical approval from the School of Sport and Health Science Ethics Committee, Cardiff Metropolitan University (reference STa-2872). This study employed a cross-sectional survey design. An online survey was developed to collect patients' experiences during the pandemic. Survey development was informed by current literature and a recent change in guidelines regarding the treatment of PA (4). This study aligns with the recent UK Patient and Public Involvement (PPI) Standards for research in terms of inclusive opportunities, working together and impact (6). Patient and Public Involvement input was gained through the PA society, 2 members were consulted from the early stages of research to ensure involvement from those who may benefit from the research (inclusive opportunities), to confirm the survey questions were clear and understandable (working together) as well as to support the dissemination of study results (impact). Eligible participants were those aged over 18 with a confirmed PA diagnosis and who were currently receiving prescribed treatment for their PA as a resident in the United Kingdom. Participants were recruited via online social media platforms including Facebook and Twitter, and the survey link was also sent out to members of the Pernicious Anaemia Society. The survey contained 15 items which were a mixture of closed questions and open-text responses (Supplementary 1). The first section of the survey collated demographic information about the respondents as well as clinical information about their PA. Participants were asked about how their PA is typically treated, and if this has changed during the COVID-19 pandemic.

Data Analysis

Survey data were analyzed using descriptive statistics, open-text responses were analyzed using content analysis (7–9) and managed through NVivo (Version 12) (10) through 1) familiarizing with the data, 2) identifying and condensing meaningful units within responses, 3) generating codes, and 4) developing categories within themes. Both authors, independently coded all the data to inductively generate themes accurately reflecting the data. Themes were revised and discussed, and where there were discrepancies (eg, code names) these were resolved by consensus to reach final themes (11). Any differences and commonalities in treatment changes

Table 1. Demographic and Clinical Characteristics of the Sample.

	N	%
Total	329	
Sex		
Female	275	83.58
Male	52	15.80
Other/missing	2	0.62
Age	47	14.28
23-39 years		
40-59 years	161	48.94
60+ years	113	34.35
Missing	8	2.43
Standard treatment		
Prescribed B ₁₂ injections within health care setting	305	92.70
Prescribed B ₁₂ injections to self-administer at home	3	0.9
Prescribed B ₁₂ injections and "top-up" at home	21	6.3
Frequency of usual treatment		
8-12 weeks	264	80.24
Other	65	19.75
Location		
England	191	58.05
Wales	50	15.19
Northern Ireland	8	2.25
Scotland	75	22.79
Location not disclosed	5	1.51

across the United Kingdom were documented. Quotes were selected to portray identified themes.

Results

The online survey was live on google forms between June 26, 2020, and October 5, 2020, and was completed by patients across the United Kingdom. In total, there were 683 responses to the survey; of these, 329 participants indicated that they had experienced a change to their prescribed treatment, which was a consequence of the pandemic. All reported percentages are based on this subsample of participants. Table 1 provides an overview of the key demographic and clinical characteristics of this sample.

Participants' ages ranged from 23 years to 87 years, and mean reported age was 53.41 ± 13.24 . There were 275 females and 52 males; one participant identified as nonbinary and one did not disclose gender. Nearly half of the participants were members of a support group to help them manage their condition. All United Kingdom countries were represented in the data, but most responses were from England (58.05%). Prior to the pandemic, all patients were receiving prescribed treatment in the form of prescribed hydroxocobalamin injections which were typically administered within a health care setting every 8 to 12 weeks. Twenty-one respondents indicated that they self-administered B₁₂ injections which they purchased alongside prescribed treatment; this was because they perceived the frequency of prescribed injections to be insufficient to manage their symptoms.

Table 2. United Kingdom Treatment Changes Due to COVID-19 With Frequencies of Codes.^a

Themes	Participant quotes	Frequency
Injections at a GP surgery with changed frequency or change to location	Had letter from GP saying reduced to 12 weekly rather than the offered 8 weeks. (P45, England)	46
Injections prescribed for self-treatment	I was sent to a different surgery for my injection and was told it was because distancing was easier there. (P7, England) Much to my surprise, a few weeks ago, a GP called me and said that I could self-administer the injections every four weeks if I were happy to be trained in how to do that. I went for an appointment with the practice nurse where she trained me and I have been giving myself the injections since then. (P11, England) <i>I was asked if I was happy to inject myself, and as I am a nurse I was pleased with this arrangement.</i> (P14, England)	37
Injections replaced with oral B ₁₂ (tablets) on prescription	My injections were cancelled and the DR prescribed B ₁₂ tablets, even though with PA my body can't absorb B ₁₂ from the tablets! (P4, Northern Ireland) I receive regular injections at the GP surgery every 8 weeks. After lockdown I was told I could not receive my injections at all and was given a "prescription" for low-grade poor-quality capsules and told to take 8 per day. Not only did these capsules upset my stomach there was a gradual decline in my health and B ₁₂ symptoms returned. (P126, Scotland)	78
Patients advised to purchase own B ₁₂ supplement	<i>It's been completely stopped. Told to take a B₁₂ supplement from a health food shop. When I have no way of absorbing it in the gut!</i> (P46, Wales)	28
Request to undergo further diagnostic tests	I was told last week due to Covid that I can't have it[injections]. Now after phoning today I'm told one doctor is looking at everyone who receives a B ₁₂ injection is being referred to one doctor for blood tests to see if we still need it. (P84, Scotland) <i>Had to fight with GP to continue[injections], at present awaiting blood results to see if injection will be stopped or continues</i> (P45, Wales)	19
No treatment received from GP surgery	<i>Treatment was completely stopped from the start of lockdown until late June and I was not offered any alternative</i> (P19, Wales)	121
Impact of treatment changes on symptoms	Fatigue increased, fuzzy brain, forgetfulness especially mid-sentence, jumbled up words (P3, Northern Ireland) ... feel so dizzy and nauseous, bad tempered and can't remember words. (P18, Scotland)	195
Emotional impact of treatment changes	Let down, undervalued, left to become ill regardless of the consequences for me or my family. (P59, England) Extremely disappointed. GPs don't seem to understand or respect how the lack of treatment can affect people (P29, Northern Ireland)	223
Total (n)		329

^a(n = 329).

Treatment Changes During the Pandemic

Precautionary measures to deal with the pandemic meant that treatment had changed for many respondents. Changes were experienced mainly by those whose usual care was to have prescribed B₁₂ administered within a health care setting. The types of treatment changes made were consistent across the United Kingdom with no apparent differences between countries. Decisions to change treatment were mostly initiated by a health care professional with no further discussion with the patient (n = 276). However, for some patients, these changes took effect after a mutual discussion between the patient and their health care provider (n = 42). A small number of individuals requested that they be provided an alternative treatment (n = 4). Often changes were temporary with patients being informed that their health care provider would revert to standard care once it was safe to do so (n = 152). A small proportion of patients had been told

that treatment changes were permanent (n = 32). Nearly half of respondents stated that they were unsure how long the change to their treatment would last (n = 143). In most cases, treatment changes meant patients' injections had been suspended and replaced with B₁₂ tablets and nutritional advice provided. The data analysis identified 8 themes related to treatment changes, which are summarized in Table 2.

Change in Frequency of Prescribed Injections

Patients who continued to receive their injections from their health care provider were often required to wait longer to receive their scheduled injections. Some patients were asked to attend a different surgery with social distancing measures in place, while others were asked to wait until their symptoms got worse before contacting their surgery to arrange their appointment.

I was told to wait another four weeks to see if pins and needles got worse/if I really needed it. When I called to speak to the GP he said he would have to make an “extreme exception” and that I was lucky as I would be the only person in the practice. (P184, England)

Injections Prescribed for Self-Treatment

It was common for patients whose injections had been suspended to request to self-treat at home. These injections would be administered by themselves, a family member, or a friend who is a health care professional. GPs supported this process by ensuring individuals were trained to safely administer B₁₂ injections at home. Patients who had been enabled to self-treat (n = 37) embraced the change to their treatment and preferred this to standard treatment. The increased perceptions of control over treatment are illustrated in the quote:

Self-injecting was as quite liberating as I am now not tied to visiting the surgery so frequently. (P2, England)

However, some requests to self-treat were not supported; in desperation to receive replacement B₁₂, these patients began to source their own injections privately or administer hydroxocobalamin injections bought overseas without a prescription (n = 12).

I used to have my injection at the surgery, but when Covid came stopped my injections so I purchased online and now self-inject. (P212, Wales)

Individuals who decided to self-treat were often able to administer injections at a treatment schedule that was more based on individual need. This group reported a noticeable improvement in their symptoms and quality of life.

I now have continual B₁₂ every day and have no symptoms from week 8 to 12 so my quality of life has improved (P221, England)
 . . . I was very tired, lethargic, my brain felt like mush, hard to concentrate and breathlessness. Since self-injecting monthly I now have
 none of these symptoms. (P5, England)

Injections Replaced With Oral B₁₂ (Tablets) on Prescription

Around a quarter of survey respondents had been prescribed B₁₂ replacement in an oral form. Patients voiced their concerns over the efficacy of this alternative source of B₁₂; it was unclear if an oral route would be effective at managing a condition caused by an inability to absorb dietary forms of B₁₂. There was a perceived lack of evidence for the effectiveness of oral supplementation at controlling symptoms. Patients felt that the advice given by health care professionals about treatment during the pandemic conflicted with their understanding of the biological basis of the condition. The

lack of confidence in the recommendation to move to oral supplementation is emphasized in the following quote . . . the surgery may just as well have given me a bag of sweets (P11, England)

Request to Undergo Further Diagnostic Tests

As a result of treatment changes, many patients reported having their injection suspended, they had been asked to undertake blood tests to confirm their need for replacement B₁₂

I was told last week due to Covid that I can't have it. Now after phoning today I'm told one doctor is looking at everyone who receives a B₁₂ injection is being referred to one doctor for blood tests to see if we still need it. (P652, Scotland)

No Treatment Received From Health Care Setting

In this sample, many respondents reported that their B₁₂ injections had been suspended; they had not received any form of treatment since the start of the pandemic and had not been offered an alternative treatment (n = 121). These patients were angry and anxious; they were concerned that suspended treatment would lead to long-term neurological damage. Patients felt this was dangerous, for one individual the change was viewed as playing Russian Roulette with my health (P7, Wales).

Impact of Treatment Changes on Symptoms

As a result of the changes in PA treatment and subsequent delays in getting treatment reinstated, many reported experiencing worse and more frequent symptoms which impacted their quality of life (n = 195).

All my symptoms worsened considerably, and I was struggling to function with daily activities and work (P144, England)

They [symptoms] are much worse than before and I have episodes that leave me bed ridden (P26, Scotland).

Those who had been moved to oral B₁₂ noticed the return of symptoms which they had not experienced since their initial PA diagnosis.

When put on tablets I developed a shaking/tremor which I remembered suffering before I was diagnosed, belatedly after about three years. (P19, England)

Further, a small number of participants mentioned developing new symptoms. The type of symptoms varied, ranging from physical to neurological symptoms.

They[symptoms] have become worse and I have new symptoms (P435, Wales)

I started to experience pins and needles in the fingers of my right hand. (P45, Scotland)

Table 3. Feelings and Emotions Experienced Due to Changes in Treatment With Code Frequencies.

Feelings and emotions	Participant quotes	Frequency
Acceptance	I felt a bit strange but was aware that there would be changes to do with access to surgery (P36, England)	36
Fear	It is an inconvenience, but I am lucky to still get my treatment (P16, Scotland)	69
	Scared, very scared. I already suffer with other illnesses which leave me already feeling unwell, to have the B12 injections stopped is going to end any sense of a quality of life (P184, England) ... frightened as it has taken me many years to get my health on an even keel (P255, England)	
Angry and upset	Very angry. I was told I needed these injections for life and now I'm told I'll be ok on tablets. (P70, England) I'm angry, I've had regular injections for 24 years... If they weren't necessary, why was I receiving them. The GP and nurses seem ill informed and lack even basic knowledge about the difference between dietary deficiency and PA (P553, Wales)	93
Let down	I feel forgotten. Like I have no control over my own health (P525, Wales)	25
	Seriously let down as the GP practice made no attempt to assess the clinical needs of individual patients to determine whether tablets were a viable alternative. (P57 England)	
	Deflated, unsupported, like I don't matter (P84, England)	
Total		223

Emotional Impact of Treatment Changes

For most individuals, changes to their usual treatment were a source of fear, anxiety, and distress (Table 3).

Many were dissatisfied with the way in which changes to treatment had been managed; the lack of shared decision-making made patients feel left out or overlooked. Only a small number of respondents reported that the decision to change their treatment had been made in response to a mutual discussion with their health care provider. This absence of shared decision-making made patients feel powerless.

Upset, angry and deeply worried. I was not consulted and have had to chase my surgery to find out what is happening at every stage (P134, England)

Discussion

This study aimed to document changes in prescribed treatment for PA during the COVID-19 pandemic. The survey revealed that many health care settings had been able to safely continue to provide patients with their usual treatment by implementing social distancing measures. These changes align with the guidance set out by the British Society for Haematology which states that during the pandemic those with PA should continue to receive hydroxocobalamin injections where possible (4). However, despite this recommendation, over half of the survey respondents reported that they had experienced a change to their usual treatment. For most patients, this meant that their treatment had been suspended or that their hydroxocobalamin injections had been replaced with oral B₁₂. Oral forms of B₁₂ were perceived to be less effective at managing symptoms.

This survey was able to document patient experiences of changes to their treatment during the pandemic across the United Kingdom. While no differences across regions were

identified in terms of treatment changes; the provision of alternative treatments varied considerably between health care settings. In some settings, patients had been supported by their health care provider to self-administer hydroxocobalamin injections, while in others prescribed treatment had been completely withdrawn. The lack of a consistent approach to managing changes for this patient group has led to a disparity in patient care. The survey highlighted that it was common for patients to have been advised to manage their B₁₂ deficiency through diet or told to purchase dietary supplements. Some health care providers had requested that patients have their B₁₂ levels re-tested to confirm their PA diagnosis and this becomes problematic. Due to the lack of reliable clinical tests for PA, it is common for this patient group to have experienced challenging diagnostic journeys (12–14), therefore requests to retest may result in additional patient distress.

The chronicity of PA and the requirement for lifelong treatment were not always considered when making treatment changes, and this has disrupted the quality of life of several patients. Responses emphasized the importance of shared decision-making and the need to communicate changes in a way that addresses patients' concerns about their health (15). Guidance by the British Society of Haematology also emphasizes the importance of discussing treatment changes during the pandemic (4). Providing patients with the opportunity to make shared decisions about their health care is empowering; however, in this sample, few participants had been involved in discussions of changes that would impact their health care. Shared decision-making can improve patient satisfaction and compliance with treatment regimens (15,16). The pandemic appears to have exacerbated existing patient concerns around discrepancies in diagnosis and management of PA within health care settings (17).

Strengths of this research relate to the in-depth account of peoples' experiences of PA treatment during the pandemic.

Patient and Public Involvement involvement added value to the research due to lived experience of the condition. While we sought a balanced representation of respondents across the United Kingdom, responses were mainly from England, which may have limited the generalizability of results. Although patients would all be treated within the National Health Service (NHS), the 4 health systems of the United Kingdom nations are devolved (18). Nevertheless, the homogeneity of responses suggests that the views collected in this survey accurately reflect the issues experienced by people with a diagnosis of PA who have experienced treatment changes during the COVID-19 pandemic.

This survey has a few limitations: the use of an online sample which was recruited in part by third-sector organizations may have led to potential self-selection bias as individuals who are unhappy with their medical care may be more likely to engage with support groups (19). It is widely acknowledged that there is often a delay in diagnosing PA and that many individuals with nondietary forms of B₁₂ deficiency struggle to receive a clinical explanation for their symptoms (13,14,17). This survey did not capture the experiences of individuals who have symptoms of nondietary B₁₂ deficiency but are not currently diagnosed with PA. As a patient group, these individuals are also likely to be impacted by the pandemic and experience challenges in accessing treatment.

This study captured patient perception of changes and although it has improved the understanding of the impact that the COVID-19 pandemic has had on PA treatment, further research is needed to explore these changes from the perspective of health care professionals. The future direction of this research is to gauge health care professionals' views on the challenges encountered in delivering replacement B₁₂ therapy during the pandemic. This study highlights the need to further educate health care professionals on the impact of PA on individuals' health-related quality of life. Development of NICE guidelines on the management of PA would also provide health care providers with clear indicators on how to support patient-centered approach to PA management.

Conclusion

Treatment changes because of the pandemic were perceived to be suboptimal to treat PA symptoms. This article highlights several learning points that can be applied to management beyond the pandemic.

- Timely communication of treatment changes would help patients further understand the reasons why alternative treatment provisions may be implemented. Treatment changes should be patient-centered and consider individual health needs.
- Changes to standard care were a source of stress and anxiety for many patients. During emergency or pandemic situations, it is important to continue with

shared decision-making and to include patients in decisions that are made about their health care.

- Health care professionals require education about PA so that changes made to treatment or care during emergency situations are evidence-based.
- Where treatment changes are required due to limited capacity within the health care service, alternative options such as self-administration of injections could be supported by adequate training to ensure patient safety.

Authors' Note

CHS and LS developed the study concept and design, data collection, analysis, and interpretation. Both authors critically revised the manuscript and agreed to be accountable for all aspects of this work. The researchers would like to be considered as joint first authors of the manuscript. The current study received ethical approval from the School of Sport and Health Science Ethics Committee, Cardiff Metropolitan University (reference STa-2872). All procedures in this study were conducted in accordance with the School of Sport and Health Sciences Ethics Committee. Written informed consent was obtained from the patient(s) for their anonymized information to be published in this article.

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Supplemental Material

Supplemental material for this article is available online.

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