Accepted Manuscript

British Journal of General Practice

Patient Safety, Self-injection and B12 Deficiency: a UK Cross-sectional Survey

Tyler, Natasha; Hodkinson, Alexander; Naeem, Ahlam; Giles, Sally; Zhou, Andrew; Panagioti, Maria

DOI: https://doi.org/10.3399/BJGP.2021.0711

To access the most recent version of this article, please click the DOI URL in the line above.

Received 21-December-2021
Revised 22-March-2022
Accepted 25-April-2022

Patient Safety, Self-injection and B12 Deficiency: a UK Cross-sectional Survey

Natasha Tyler, PhD, Research Fellow, corresponding author (Natasha.tyler@manchester.ac.uk) 0000-0001-8257-1090 [12]

Alexander Hodkinson, PhD, Research Fellow, 0000-0003-2063-0977 [12]

Naeem, Ahlam, Medical Student[3]

Sally Giles, PhD, Research Fellow, 0000-0003-1623-6029 [1]

Andrew Zhou, BA (Hons), Medical Student [4]

Maria Panagioti, PhD, Senior Lecturer in Primary Care, 000-0002-7153-5745 [12]

[1]NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, M13 9PL

[2]NIHR School for Primary Care Research, University of Manchester, Manchester, M13 9PL

[3]University of Manchester, Manchester, M13 9PL

[4]School of Clinical medicine, University of Cambridge, CB2 0SP

Background

Individuals with vitamin B12 deficiency (including pernicious anaemia) often report being 'let down' or stigmatised by general practice systems and policy and chose to instead self-medicate via injection, the association between this and perceptions of safe primary care in this group of people is unknown.

Aim

To examine the association between self-medication and patient-reported safety in primary care

Design and Setting

A UK cross-sectional online survey.

Methods

Survey consisted of the three components: a) demographics, b) the validated Primary Care Patient Measure of Safety, and c) questions about self-medication. Multivariable logistic regression analyses and thematic synthesis were undertaken.

Results

Responses from 1,297 participants, indicated 508 (39%) self-medicated via injection. Perceived primary care safety was low. Those who self-medicated via injection reported a significantly lower level of patient safety in primary care including adverse patient-related factors (OR=0.82, 95%CI: 0.73 to 0.92), and patients over the age of 34 were significantly more likely to self-medicate via injection. Many reported treatment under the guidance of a clinician was preferable, but felt they had no other choice to regain quality of life. Almost half felt the doctor did not always consider what they wanted for their care.

Conclusion

The largest study to date examining patient safety and vitamin B12 deficiency found that four out of 10 patients with B12 deficiency self-medicate via injection. Patients who self-medicated, perceived primary care as less safe. Providing patient-centred care and treating these patients with dignity and respect is a policy priority to reduce unsafe health behaviours.

How this fits in

It is known that individuals with vitamin B12 deficiency (including pernicious anaemia) describe their primary care consultations as 'battles' and feel stigmatised. However, the extent of this dissatisfaction with primary care and the effect this might have on patient safety and unsafe health behaviours is unknown. This is the first study to assess the association between patient reported safety and self-medication via injection and to consider the contributory factors to patient safety that affect this patient group. Understanding any negative effects of current practice and how general practitioners and primary care clinicians can better meet the needs of this marginalised group is key, to improving safety and care.

Background

Vitamin B12 deficiency (B12d) is a hidden condition that affects the quality of life of many people in the United Kingdom (UK) [1]. It has an estimated prevalence of roughly 6% in the UK [2]. People with B12d are primarily managed in primary care. Guidelines for diagnosis and treatment of B12d are inconsistent and many people are unable to access treatment [3].The most common cause of B12d is pernicious anaemia (PA), an autoimmune disorder that results in inflammation and damage to the stomach lining [4].

The deficiency is usually treated with injections of vitamin B12, in a form called hydroxocobalamin [5]. Individuals must demonstrate deficiency in the diagnostic blood test to qualify for treatment but types of blood tests and 'cut-off' rates vary. Many patients describe their pressing need to access treatment as a continuous 'battle' [6,7]. As a result many people decide to self-medicate via injection (SMVI), without their general practitioner's (GP) knowledge or guidance and purchasing B12 ampules overseas without a prescription [8]. Self-medication guided by GPs has numerous benefits such as reducing the primary care burden and improving patient empowerment. However unguided self-medication has many potential risks such as incorrect self-diagnosis, dangerous drug interactions, incorrect manner of administration, severe adverse reactions and masking of severe disease [9]. An increasing number of GPs and patients advocate for changes to policy and practice that enables self-management of the disorder, including self-injection [7,10].

Patient safety is a recognised concern in primary care [11] especially for marginalised groups such as people with B12d [12]. The most common contributory factors to safety in primary care are the quality of communication, diagnostics and medication management [11]. Patient reported instruments have been developed and validated to identify the contributory factors to patient safety incidents in primary care [13,14]. Individuals with B12d/, may be at greater risk of patient safety incidents in primary care as they often describe suboptimal communication, lack of dignity and respect and feelings that healthcare professionals lack the knowledge, skills and attitudes to adequately treat their condition [6,13,15,16].

Objectives

1. Examine the association between patient-reported safety in primary care (with a focus on quality of communication and dignity) and self-medication in people with B12d controlling for clinical factors and socio-demographic factors;
2. Explore patient experiences surrounding self-medication and treatment changes following the Covid-19 pandemic.

Methods

Design

This cross-sectional study consisted of an online questionnaire, distributed by individual participant generated (unique) link using 'Select Survey'. Data were anonymously collected from 16/07/2020 to 21/07/2020. We adhered to STROBE statement guidance for reporting on cross-sectional studies [17].

Sample

Participants were recruited using advertisements in social media support groups for individuals with B12d/PA (see acknowledgements). The only inclusion criteria for participation was diagnosis of B12d/PA, this was an initial screener question, if a diagnosis was not declared, one could not continue, there was no restrictions on length of diagnosis. We recruited participants from England, Wales, Scotland, Northern Ireland and the Republic of Ireland. It was decided a priori that the questionnaire would only remain open for 6 days, as this was exploratory there were no study size decisions made a priori.

Measures

The questionnaire consisted of three sections: 1) Demographics, 2) Primary Care Patient Measure of Safety, and 3) Self-Medication.

Sociodemographic characteristics

Diagnosis (B12d or PA) age, gender, education level, employment status, country of residence (England, Wales, Scotland, Northern Ireland, Republic of Ireland), region of residence (9 English regions according to the ONS, Wales, Scotland and Northern Ireland) were assed using questions in supplementary table 1. We included a single item literacy screener (SILS) to evaluate health literacy [18] and a single item measure of health status [19] 'How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?' Diagnosis (B12d or PA) was treated as a binary response in analysis, as everybody in the PA group was also classed as having vitamin B12 deficiency, as PA is the most common cause of B12d [4].

Patient reported safety in primary care

A validated 28-item questionnaire was used to assess patient-reported contributory factors to safety in primary care (PCPMOS) [13][14]. The measure has 10 domains: Dignity; Patient related factors; Task performance; Communication; Access; Information flow; External policy context; Organisation and care planning; Referrals; Physical environment. Some items were reverse coded, a larger score on each subscale indicates higher patient perceived safety. The measures demonstrated good discriminant validity between primary care practices ($F = 2.64$, $df = 72$, $p < 0.001$) and good internal validity for the domains, Cronbach's alphas for most scales were above 0.70. The scale almost demonstrated convergent validity, with a positive association with a staff measure of patient safety (AHRQ MOS[20]). There was no difference in total PCPMOS scores for the diagnosis groups, see table 2.

Self-medication

The measure for the dependant variable self-medication via injection was developed for the purpose of this study. The questions were inspired by questionnaires from other self-medication questionnaires [21,22] and patient and public engagement [16]. SMVI was assessed using two items. Firstly 'In general apart from treatments prescribed by your doctor do you sometimes take medications on your own to treat your B12 deficiency?' response options 'Yes' or 'No'. Followed by 'If yes, which of the following do you take? (in addition to anything prescribed) with four responses 'self-injection', 'oral medication in tablet form' 'oral medication in liquid form', 'other, please state'. Individuals who answered yes item 1

and 'self-injection' to item two were coded as 1, all other responses were coded as 0. In addition we asked six multiple choice questions (Supplementary table 1).

Free Text Questions

We included one free text question to gain a deeper understanding of circumstances around self-medication, 'Do you have any concerns about safety and self-medication?' There were also three other free text questions in regards to treatment type that they patients were receiving, treatment frequency and the effects of the SARS-CoV-2 pandemic on their treatment.

Analysis

Descriptive statistics included the number of participants and percentages of the total survey sample. The association between discrete variables with diagnosis (i.e., B12d/PA diagnosis) or self-medication (yes/no) was assessed by cross-tabulation and statistically by Pearson's X^2 test or fisher exact test. Only two participants had a missing primary outcome, which was imputed using MICE [23]. To estimate the strength of the association, univariable (binary) logistic regression models were used to calculate the odds ratio (OR). Then a multivariable regression analysis was done using the relevant variables associated with self-medication at the α-level of $P<0.10$ from our univariable analysis. Confidence intervals (CIs) reported are likelihood based. All p-values were 2-sided, and we regarded $P<0.05$ as significant in the final multivariable model. The *stats* package in R was used for the regression analysis. A Bayesian generalized linear model was used to check the consistency of the regression results using the R package *rstanarm*. Specifically, we used Markov Chain Monte Carlo sampling with 4 chains of 2,000 iterations. Uninformative priors were used for the parameter in all models. All analyses were performed using R version 4.0.5 (R Foundation for Statistical Computing). For the corresponding primary outcome (SMVI), we imputed any missing values using the R package 'MICE: Multivariate Imputation by Chained Equations' [23] following Rubin's principle for imputation[24]. The baseline covariates (age, gender, and ethnicity) were used to predict missing data.

Open-text responses were analysed using thematic synthesis; which consists of three stages: line-by-line coding of text, development of descriptive themes and generation of analytical themes (as outlined in Thomas and Harden, 2008) [25]. The analytical themes were an overall judgement in response to the question (i.e. affected by Covid-19 or not affected by Covid-19).

Results

Descriptive Characteristics

The key characteristic of the 1297 respondents are reported in Table 1. The sample was almost exclusively female, (n=1230, 95%) and over 82% of participants were aged 35 and over (n=1075). Approximately half of the sample had a diagnosis of PA (n=639, 49%), the remainder had a B12d diagnosis only. Approximately 3 in 20 participants reported health literacy problems at least occasionally (i.e. sometimes to always). Almost half of the

participants were college or University educated (n=568, 44%) and 65% were employed (n=846). The areas of the UK and Ireland with the biggest representation were North West (197, 19%), South East (165, 16%) and Wales (134, 13%).

The characteristics of the sample did not significantly differ between those with a diagnosis of B12d compared to PA, see appendix table 2. However, the association between self-medication and diagnosis type was significant (P=0.002). There was also a significant difference between self-medication via injection and diagnosis (P=0.016).

As many as 803 (62%) of the 1297 respondants self-medicated with the majority via injection (n=508, 39%). Of the 803 who self-medicated, 63% self-injected and a few medicated using various oral methods. The most common reason for self-medicatation was to improve quality of life (n=644, 80%), followed by dissatisfaction with treatment frequency (n=545, 68%). Other reasons included concerns about over-relianiance on tests (n=429, 53%) and lack of trust in healthcare professionals (n=366, 45%), The most common source of information was an online closed support group (n=577, 72%). Few participants that self-medicated informed a healthcare professional (54% did not). No participants reported side effects and the main symtoms participants aimed to improve were fatigue (n=762, 95%), concentration/brain fog (n=697, 95%) and pins-and-needles (n=629, 78%), see supplementary table 2.

In terms of patient reported safety in primary care, our sample had poorer perceptions of safety than the sample used in the PCPMOS validation study [13]. , This is indicated by the mean total PCPMOS scores and the mean scores of the individual domains (supplementary table 3). Participants reported numerous safety concerns (figure 2 and supplementary table 4). For example, only 50% of participants agreed that they were always treated with dignity/respect, 49% disagreed that the doctor always considered what they wanted for their care, 44% did not feel involved in decisions, 56% did not feel listened to, 42% felt they did not receive enough information, and only 18% felt they got answers to all questions about their care. Only 31% felt staff knew everything they need to care for them.

Association between perceived primary care safety and self-medication by injection

The univariable logistic regression analysis showed that a lower total PCPMOS score (OR=0.97, 95% CI=0.97 to 0.98) and lower scores on the individual domains (indicating lower perceived patient safety) were significantly associated with higher odds for SMVI (supplementary table 5). Other variables significantly associated with increased odds for SMVI included a lower (poor/fair) health status (OR=1.46, 95% CI=1.14 to 1.88) older age (over 45 years) and a pernicious anaemia diagnosis (OR=0.76, 95% CI=0.61 to 0.95).

In multivariable regression analyses (figure 1), two PCPMOS domains including Patient Related Factors (OR=0.82, 95% CI: 0.73 to 0.92), Information Flow (OR=1.10, 95% CI: 1.01, 1.21) and External policy Context (OR=1.10, 95% CI: 1.01, 1.19) remained significantly associated with SMVI (Supplementary table 6). All ages over 34 remained significantly associated with self-medication (age groups: 35-44, OR=1.49, 95% CI: 1.01, 2.20; 45-54, OR=2.06, 95% CI: 1.42, 3.02; 55-64, OR=2.31, 95% CI: 1.51, 3.55; 75 and above, OR=2.80, 95% CI: 1.61, 4.91. Variance inflation factor estimates indicated that total PCPMOS was 4.16, which indicate that this variable is moderately correlated with other

variables in the model. The regression results which were checked through Bayesian inference, showed very similar results (Figure 3).

Thematic synthesis of patient concerns about self-medication and treatment implications of the Covid-19 pandemic

Six-hundred-and-thirty-eight respondents completed the open-text question about self-medication concerns, 386 (60%) were not concerned about self-medication. The key thematic reasons for this were 1) Experience, 2) Lack of trust in GPs, 3) Improved Quality of Life, 4) Adherence to guidelines, 5) Credibility of sources. The concerned group (192, 30%) had five key concerns: 1) Preference of health professional administration, 2) No other choice, 3) Complications, 4) Storage and disposal, 5) Financial concerns. The remaining 60 (9%) responses were classified as indifferent or concerned. The indifferent group presented three key themes 1) Overcoming initial fears, 2) Social Support, and 3) Type of Injection, see supplementary table 7.

Over half of the sample felt the Covid-19 pandemic affected their care (749, 58%). There were 7 key themes surrounding those not affected 1) Self-medication; 2) Proactive GP; 3) Proactive Patient; 4) Receiving treatment in car; 5) Alternative treatment sufficient; 6) Direct contact with nurse practitioner; 7) Location. For those affected there were 6 key themes 1) Appointment difficulties; 2) Treatment stopped or cancelled; 3) Monitoring and diagnosis stopped; 4) Alternative treatments not available; 5) Delayed/reduced frequency of injections; 6) Effect on daily activities,

Discussion

Summary

We found that 4 in 10 people with B12d/PA self-medicate via injection and have lower than average perceptions of primary care safety. Those who SMVI perceived primary care as less safe and specifically they did not feel they are treated with dignity/respect or involved in decisions. Middle aged and older participants were more likely to SMVI compared to younger participants.

The two most common reasons why participants chose to SMVI were to improve quality of life (80%) and due to dissatisfaction with current treatment frequency (68%). Our research also highlights that the main source of information about self-medication is online closed support groups (72%).

Many of the participants did not want to SMVI and would prefer to be medicated under medical guidance, but felt they had no choice, as they wanted to regain quality of life. In line with similar research [10], 6 in 10 people experienced difficulties receiving their essential treatment during the pandemic.

Strengths and Limitations

This is the first large scale UK survey to assess patient safety in primary care for this patient group. However, participants were recruited from social media groups, which may a) not be

representative of the older population who have a greater B12d prevalence and may use primary care frequently and b) be more exposed to discussions around self-medication. The cross-sectional nature of this study means that no causal inferences can be made about the direction of the associations. Furthermore, this study was conducted during the initial stages of the SARS-CoV-2 pandemic, many general practices stopped treatment [10], however qualitative results show that SMVI was common before.

This study relies on self-reported diagnosis and recruitment from online support groups which evidence suggests has some limitations. Groups sometimes have a high proportion of individuals who are struggling to gain a clinical diagnosis within primary care [26]. Self-reported diagnosis could be representative of subclinical cases, misdiagnosed individuals, or individuals who incorrectly attribute their symptoms [26]. Research also, suggests individuals in online communities may influence one another and potentially reaffirm negative views of healthcare systems [27] .

Comparison with existing literature

This is the first large survey examining perceived quality and safety in primary care for people with B12d/PA. Our findings show that SMVI, is an important safety concern often associated with suboptimal communication, feeling undignified in care interactions and perceived lack of clinician knowledge or trustworthiness. The presence of these contributory factors is consistent other research whereby patients described 'battles' and stigmatisation from practitioners [6].

Patient safety for marginalised groups in primary care is a growing empirical field [13]. Incident reporting systems are criticised due to under-reporting patient safety incidents and a tendency to focus on the proximal causes of incidents [28–31]. Our research highlights the importance of patient reported safety in primary care because they highlight issues that clinicians may not recognise [32] and provide a framework for future directed learning to reduce safety incidents [15,33]

Implication for research and/or practice

Estimates suggests 1 in 20 people under 60 in the UK have B12d.; this equates to roughly 3.4 million people, however 20% of over 60s could be affected [2]. This is a marginalised group in terms of accessing care and our findings indicate that 4 out of 10 choose to SMVI; which unguided is an unsafe practice.

Our findings also suggest that self-injection might be driven by poor perception of primary care safety and especially low perceived dignity and respect. The National Institute for Health and Care Excellence (NICE) guidelines for PA are due to be published in 2023 (29). There is a major need to develop/improve universal nationwide diagnosis and treatment policies for vitamin B12d in primary care. Such universal policies could reduce regional treatment discrepancies and help improve the relationships of these patients with their GP and reduce unguided self-medication. Finally, efforts to reduce the perceived stigma [6] associated with this condition and encouraging clinicians to practice patient-centred care, driven by symptom recognition as opposed to reliance on suboptimal testing, could also increase patient safety. Future research should aim to confirm these results with more rigorous sampling methods and assess the perspectives of primary care practitioners in response to these results.

Funding

There was no funding for this work. The time of MP and NT was funded by the National Institute for Health and Care Research (NIHR) Greater Manchester Patient Safety Translational Research Centre (award number: PSTRC-2016-003). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Ethical Approval

The project has been reviewed by the University of Manchester Research Ethics Committee. UREC ref: 2020-9782-15565

Competing Interests

The authors declare no competing interests.

Acknowledgements

We would like to thank Pat Kornic and the Pernicious Anamia/B12 Deficiency Support Group and Tracey Witty and the B12 Info group (https://m.facebook.com/b12info/).

References

[1] NICE. Active B12 assay for diagnosing vitamin B12 deficiency. NICE; 2015. https://www.nice.org.uk/advice/mib40/chapter/Introduction (accessed 28 March 2022)

[2] Hunt A, Harrington D, Robinson S. Vitamin B12 deficiency. BMJ 2014;349:g5226. https://doi.org/10.1136/bmj.g5226.

[3] Devalia V, Hamilton MS, Molloy AM. Guidelines for the diagnosis and treatment of cobalamin and folate disorders. Br J Haematol 2014;166:496–513. https://doi.org/10.1111/bjh.12959.

[4] Andres E, Serraj. Optimal management of pernicious anemia. J Blood Med 2012;3:97. https://doi.org/10.2147/jbm.s25620.

[5] Van Uden-Kraan CF, Drossaert CHC, Taal E et al. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008;18:405–17. https://doi.org/10.1177/1049732307313429.

[6] Seage CH, Glover E, Mercer J. Receiving a Diagnosis of Pernicious Anemia: Exploring Experiences of Relationships With Health Professionals. J Patient Exp 2019:237437351988349. https://doi.org/10.1177/2374373519883497.

[7] Warren J. Pernicious anaemia: self-administration of hydroxocobalamin in the covid-19 crisis. BMJ 2020;369. https://doi.org/10.1136/BMJ.M2380.

[8] Kornic PA, Harty MMJ, Grant JA. Influence of treatment parameters on symptom relief in individuals with vitamin B12 deficiency. Annu Res Rev Biol 2016;11. https://doi.org/10.9734/ARRB/2016/31711.

[9] Ruiz M. Risks of Self-Medication Practices. Curr Drug Saf 2010;5:315–23. https://doi.org/10.2174/157488610792245966.

[10] Seage CH, Semedo L. 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. Journal of Patient Experience. 2021;8: https://DoiOrg/101177/2374373521998842.

[11] Panesar SS, Desilva D, Carson-Stevens A, Cresswell KM, Salvilla SA, Slight SP, et al. How safe is primary care? A systematic review. BMJ Qual Saf 2016;25:544–53. https://doi.org/10.1136/bmjqs-2015-004178.
[12] Cheraghi-Sohi S, Panagioti M, Daker-White G, et al. Patient safety in marginalised groups: a narrative scoping review. Int J Equity Heal 2020 191 2020;19:1–26. https://doi.org/10.1186/S12939-019-1103-2.
[13] Giles SJ, Parveen S, Hernan AL. Validation of the Primary Care Patient Measure of Safety (PC PMOS) questionnaire. BMJ Qual Saf 2019;28:389–96. https://doi.org/10.1136/bmjqs-2018-007988.
[14] Hernan AL, Giles SJ, O'Hara JK. Developing a primary care patient measure of safety (PC PMOS): A modified Delphi process and face validity testing. BMJ Qual Saf 2016;25:273–80. https://doi.org/10.1136/bmjqs-2015-004268.
[15] Hernan AL, Giles SJ, Fuller J. Patient and carer identified factors which contribute to safety incidents in primary care: A qualitative study. BMJ Qual Saf 2015;24:583–93. https://doi.org/10.1136/bmjqs-2015-004049.
[16] Tyler N, Giles S, Daker-White G, Panagioti M. Using visual art and priority setting to provide patients with a voice to describe quality and safety concerns: vitamin B12 deficiency and pernicious anaemia (under review). Heal Expect 2021.
[17] Von Elm E, Altman DG, Egger M,. et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. Ann Intern Med 2007;147:573–7.
[18] Morris NS, MacLean CD, Chew LD, Littenberg B. The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. BMC Fam Pract 2006 71 2006;7:1–7. https://doi.org/10.1186/1471-2296-7-21.
[19] Idler EL, Russell LB, Davis D. Survival, Functional Limitations, and Self-rated Health in the NHANES I Epidemiologic Follow-up Study, 1992. Am J Epidemiol 2000;152:874–83. https://doi.org/10.1093/AJE/152.9.874.
[20] Agency for Healthcare Research and Quality. Surveys on patient safety culture research reference list, Rockville, MD. n.d. https://www.ahrq.gov/sops/surveys/medical-office/index.html (Accessed 28 March 2022)
[21] Lukovic JA, Miletic V, Pekmezovic T. et al. Self-medication practices and risk factors for self-medication among medical students in Belgrade, Serbia. PLoS One 2014;9. https://doi.org/10.1371/journal.pone.0114644.
[22] Sridhar S, Shariff A, Dallah L. Assessment of nature, reasons, and consequences of self-medication practice among general population of Ras Al-Khaimah, UAE. Int J Appl Basic Med Res 2018;8:3. https://doi.org/10.4103/ijabmr.ijabmr_46_17.
[23] van Buuren S, Groothuis-Oudshoorn K. mice: Multivariate imputation by chained equations in R. J Stat Softw 2011;45:1–67. https://doi.org/10.18637/jss.v045.i03.
[24] Rubin DB, Wiley J, York N, Brisbane C, Singapore T. Multiple Imputation for Nonresponse in Surveys 1987. https://doi.org/10.1002/9780470316696.
[25] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol 2008;8:45. https://doi.org/10.1186/1471-2288-8-45.
[26] Lewis LF. Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults. Arch Psychiatr Nurs 2016;30:575–80. https://doi.org/10.1016/J.APNU.2016.03.009.
[27] Giles DC, Newbold J. Self- and other-diagnosis in user-led mental health online communities. Qual Health Res 2011;21:419–28. https://doi.org/10.1177/1049732310381388.

[28] Giles S, Panagioti M, Hernan A, Cheraghi-Sohi S, Lawton R. Contributory factors to patient safety incidents in primary care: protocol for a systematic review. Syst Rev 2015 41 2015;4:1–7. https://doi.org/10.1186/S13643-015-0052-0.
[29] Vincent C. Incident reporting and patient safety.BMJ. 2007. 334 (7584):51.
[30] Shojania, KG. The frustrating case of incident-reporting systems.BMJ Qual Saf 2008;17:400-402. https://doi.org/10.1136/qshc.2008.029496.
[31] Avery AJ, Anderson C, Bond CM. et al. Evaluation of patient reporting of adverse drug reactions to the UK "Yellow card scheme": Literature review, descriptive and qualitative analyses, and questionnaire surveys. Health Technol Assess (Rockv) 2011;15:1–234. https://doi.org/10.3310/hta15200.
[32] Lawton R, Armitage G. The role of the patient in clinical safety. Heal Found 2012:11.
[33] Reason J. Understanding adverse events: human factors. BMJ Qual Saf 1995;4:80–9.

Table 1: General demographics of survey participants (n=1297)

Variable	N (%)
Age (yrs.):	
- 18-34 yrs.	222 (17)
- 35-44 yrs.	337 (26)
- 45-54 yrs.	426 (33)
- 55-64 yrs.	224 (17)
- 65 yrs. and older	88 (6.8)
Women n (%)	1230 (95)
Education level:	
- College or university	568 (44)
- Higher or secondary or further education	260 (20)
- Post-graduate	223 (18)
- Prefer not to say	44 (3.4)
- Primary and Secondary school	192 (14.8)
Employment status:	
- Employee or self-employed	846 (65.2)
- Other	451 (34.8)
Region:	
- East Midlands	67 (6.4)
- East of England	39 (3.7)
-Ireland	21 (1.6)
- London	37 (3.6)
- North East	57 (5.5)
- North West	197 (18.9)
- Northern Ireland	17 (1.6)
- Scotland	41 (3.9)
- South East	165 (15.9)
- South West	130 (12.5)
- Wales	134 (12.9)
- West Midlands	69 (6.6)
- Yorkshire/Humberside	88 (8.5)
Diagnosis of Vitamin B12 Deficiency	879 (68)
Diagnosis of Pernicious Anaemia	639 (49)
Require support to read instructions, pamphlets, or other written material:	
- Always/Often	44 (3.4)
- Sometimes	134 (10)
- Rarely	134 (10)
- Never	985 (76)

Table 1: Characteristics of people with B12 deficiency including self-medication status/safety, type of diagnosis (B12 vs PA), general health status and health literacy levels

	Diagnosis		
	Vitamin B12 Deficiency	Pernicious Anaemia	
Variable	**N (%)**		**χ^2, P-value***
Heath status:			
- Good/Excellent	207 (16)	181 (14)	χ^2 = 1.518, P=0.218
- Fair/Poor	451 (35)	458 (35)	
Heath Literacy:			
- Always/Often	24 (1.9)	20 (1.5)	χ^2 = 1.761, P=0.624
- Sometimes	63 (4.9)	71 (5.5)	
- Rarely	73 (5.6)	61 (4.7)	
- Never	498 (38)	487 (37.5)	
Country of residence (region):			
- *East midlands*	36 (3.5)	31 (3)	χ^2 = 15.839, P=0.147
- *East of England*	21 (2)	18 (1.7)	
-Ireland	12 (0.9)	9 (0.7)	
- *London*	15 (1.4)	22 (2.1)	
- *North East*	19 (1.8)	38 (3.7)	
- *North West*	96 (9.2)	101 (9.7)	
- *Northern Ireland*	10 (1)	7 (0.7)	
- *Scotland*	16 (1.5)	25 (2.4)	
- *South East*	87 (8.4)	78 (7.5)	
- *South West*	76 (7.3)	54 (5.2)	
- *Wales*	68 (6.5)	66 (6.3)	
- *West Midlands*	31 (3)	38 (3.7)	
- *Yorkshire/Humberside*	44 (4.2)	44 (4.2)	
Country of residence:			
- England	522 (40)	509 (39)	χ^2 = 0.021, P=0.885
- Wales	136 (11)	130 (10)	
Self-medication:			
- Yes	435 (34)	368 (28)	χ^2 = 9.997, **P=0.002**
- No	222 (17)	270 (21)	
Self-medication via injection:			
- Yes	279 (21.5)	229 (17.7)	χ^2 = 5.862, **P=0.016**
- No	397 (28.6)	445 (32)	
PMOS total			**t_{1298} = -17.42, P=0.071

*Person's chi-squared test for all factors.

**paired t-test.

Figure 1: Stacked bar chart to show medication via injection across regions

Figure 2 Likert Plot of PCPMOS responses

Figure 3: Multivariate regression plot of the factors associated with self-medication by injection