# Understanding the Patient PPI Journey: Results of a Survey on PPI Treatment Initiation and Patient Experience

Journal of Primary Care & Community Health Volume 13: 1–7 © The Author(s) 2022 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/21501319221088688 journals.sagepub.com/home/jpc SAGE

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#### Abstract

Introduction: Proton pump inhibitors (PPIs) used in the management of gastro-esophageal reflux disease (GORD) are among the most frequently prescribed classes of drug worldwide. Currently, however, physicians are prescribing PPIs for extended periods, often without an indication, which is not in line with current guidance and therefore preventing appropriate reflux management. Inappropriate or excessive PPI prescribing is becoming increasingly visible, yet there is currently little research available on the impact such current practice has on the patient experience. This study aims to understand patient attitudes toward their PPI treatment and the impact current PPI prescribing patterns have on the patient experience. Methods: An online survey of current and previous users of PPI for GORD was conducted in the UK and Germany. Topics covered included prior steps taken before first consultation with a physician, initial recommendations, PPI treatment initiation and duration, use of PPI, management of reflux whilst taking a PPI, stopping PPI treatment, and patient attitudes. Results: Among 566 patient participants (UK, n=372; Germany, n=194) 69% to 79% reported being prescribed medication at their first visit to a physician, of which 61% to 68% were prescribed a PPI either alone or combined with another treatment. 41% to 48% of patients answered "don't know" when asked how long they expected to continue taking their PPI. 49% to 50% of patients currently on PPIs also reported having concerns with regards to long-term treatment. 70% of patients recalled being well informed on dosage and treatment regimens. However, other safety and usage information was reported as being less frequently discussed. Conclusions: Although patients reported concerns regarding ongoing long-term PPI treatment, this was not reflected in the prescribing pattern from physicians. More can be done to ensure patients are fully informed about their PPI treatment at consultation. Findings also suggest a disconnect exists between standard treatment guidelines and prescribing patterns, as experienced by patients.

#### **Keywords**

lifestyle change, medications, primary care, proton pump inhibitor, gastroenterology, patient experience

Dates received: 4 January 2022; revised: 22 February 2022; accepted: 23 February 2022.

## Introduction

Proton pump inhibitors (PPIs) irreversibly inactivate the active form of the proton pump (H<sup>+</sup>-K<sup>+</sup>-ATPase), suppressing both stimulated and basal acid secretion.<sup>1</sup> Since their clinical introduction during the 1980s, PPIs have become one of the most frequently prescribed drug classes worldwide.<sup>2-4</sup> Although they are indicated for the treatment of gastro-esophageal reflux disease (GORD), current guidelines recommend that patients with GORD, or uninvestigated dyspepsia initially be offered lifestyle advice, such as healthy eating, weight reduction, and quitting smoking, before trying non-systemic over-the-counter (OTC) therapies such as antacids and alginates if

symptoms are not adequately controlled.<sup>5,6</sup> In those with persistent symptoms despite lifestyle interventions and/or non-systemic therapies, full dose PPI treatment should be given for a course of 4 to 8 weeks<sup>7,8</sup> and then deprescribed in patients in whom symptoms resolve.<sup>9</sup> This stepwise approach is considered appropriate reflux management. For patients with an indication for long-term therapy, the

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Topic area	Group I	Group 2	Group 3
Steps taken before first visiting physician for reflux	✓	1	×
Initial recommendations	$\checkmark$	1	X
PPI treatment initiation	$\checkmark$	1	1
Use of PPI	$\checkmark$	1	$\checkmark$
Management of reflux whilst taking a PPI	$\checkmark$	1	X
Ending PPI treatment	$\checkmark$	1	$\checkmark$
Attitudes toward taking a PPI	$\checkmark$	1	X

 Table I. Topics Covered by Sample Groups.

lowest effective PPI dose should be prescribed, and PPI use should be reviewed regularly.<sup>5,8,10</sup>

The effectiveness of PPIs has led to overuse in multiple acid-related conditions, including GORD.<sup>11</sup> Contrary to the guidance outlined above, physicians often prescribe PPIs as first-line agents for acid-related conditions,<sup>12</sup> and for extended periods without review, with a large proportion of patients remaining on PPIs for over 1 year.<sup>13</sup> Consequently, this presents a barrier to appropriate reflux management. Although a growing number of reports on PPI use demonstrate that this is an issue recognized academically, it is yet to be addressed in clinical practice. Not only are PPIs overprescribed, but many PPI long-term users do not have an appropriate indication for treatment; 30% to 96% of those taking PPIs for over 1 year may not have a diagnosis compatible with treatment.<sup>3,14,15</sup> PPIs are also more commonly prescribed at high doses rather than the lowest effective dose where long-term treatment is warranted.<sup>16-18</sup>

Although PPIs have a very good safety profile for shortterm treatment, there is uncertainty regarding their longterm use. Increasing long-term use of PPIs without a proper indication may have clinical implications that, until recently, have not attracted much attention, but are beginning to be more frequently recognized.<sup>14</sup> Despite normalized long-term use, a majority of patients may be eligible to reduce or discontinue their PPI dose.<sup>2,19,20</sup> However, no attempt is made to deprescribe PPIs in 60% to 88% of long-term users,<sup>21,22</sup> even though patients are often willing to adjust their usage.<sup>23</sup>

Most publications have focused on the use of PPIs from a clinical perspective, yet few studies have addressed the impact of current PPI prescribing practice from a patient perspective. In this study, we aimed to evaluate patients' experiences of and attitudes toward PPI initiation and treatment, as well as the patterns of PPI prescribing. Understanding patient attitudes toward current PPI prescribing practice is crucial for achieving optimal care for patients experiencing reflux symptoms and helping to address the issue of PPI misuse.

## Methods

An online survey was conducted by a specialist market research company in the UK and Germany in December 2019. Participants had signed up to answer online surveys on any topic and were sourced via the market research UK and Germany panels. Data were anonymized, and no data were obtained via healthcare records; all involvement was voluntary from individuals participating in the market research panel.

The self-completed survey included multiple-choice questions on baseline demographics, management approaches prior to starting PPI treatment, use of PPIs, management of symptoms whilst taking PPIs, attitudes toward PPIs and PPI discontinuation. The questions were either in English or German.

Patients first answered screening questions and, depending on whether they qualified for inclusion in the survey, proceeded to answer the survey questions. Patients qualified for inclusion in the survey if they fell into at least 1 of 3 sample groups: (1) current users of PPI to treat reflux at the time of the survey; (2) previous users of PPI to treat reflux in the last year; or (3) previous users of PPI for another reason in the last year. Current users of PPIs for any other reason were excluded from the survey. Qualifying patients were given the opportunity to proceed with the survey, and completed a 5- or 20-min survey based on the sample group. Those in groups 1 and 2 completed the 20-min survey, whereas those in group 3 completed the 5-min survey. The topics covered in the survey varied depending on the sample group (Table 1). The full survey is provided in Supplemental Material 1.

#### Results

### Survey Population

A total of 10728 patients were screened, of which 6088 were from the UK and 4640 from Germany. Of these patients, 566 (5.3%) met all the inclusion criteria for participation in the survey, with 372 patients from the UK and 194 from Germany. The mean age of UK participants was 53.94 years (standard deviation [SD]: 15.29), with ages ranging from 19 to 83 years. The mean age of German participants was similar at 51.38 years (SD: 14.31), with ages ranging from 18 to 81 years. The majority of patients (82.5% UK; 71.6% Germany) were current users of PPI for reflux.

Table 2.	Characteristics	of Survey	<sup>,</sup> Population.
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	UK n=372	Germany n = 194
Gender, n (%)		
Male	143 (39.0)	73 (38.0)
Female	228 (61.0)	121 (62.0)
Education level, n (%)		
No qualifications	17 (4.6)	I (0.5)
High school	88 (23.7)	68 (35.1)
Apprenticeship/vocational training	45 (12.1)	58 (29.9)
College/sixth form or equivalent	74 (19.9)	27 (13.9)
Bachelor's degree or equivalent	55 (14.8)	33 (17.0)
Postgraduate degree	38 (10.2)	5 (2.6)
Other	55 (14.8)	2 (1.0)
Employment status, n (%)		
Employed	193 (51.9)	107 (55.2)
Homemaker	37 (9.9)	12 (6.2)
Student	2 (0.5)	3 (1.5)
Retired	101 (27.2)	63 (32.5)
Unemployed	39 (10.5)	9 (4.6)
PPI use, n (%)		
Currently using a PPI for reflux	307 (82.5)	139 (71.6)
Previously used a PPI for reflux	51 (13.7)	42 (21.6)
Previously used a PPI for another condition	14 (3.8)	13 (6.7)
Age (mean $\pm$ SD)	53.94 (15.29)	51.38 (14.31)

Characteristics of the survey population are detailed in Table 2.

#### Treatment Initiation

A majority of UK (79%) and German (69%) reflux patients reported being prescribed medication for reflux on their first visit to a physician. Of these, 61% in the UK and 68% in Germany were prescribed a PPI either alone or in combination with another treatment. Approximately 19% of patients (20% UK; 17% Germany) reported not having tried any OTC medication prior to being prescribed a PPI. Among those not receiving medication, more German patients reported that they had received lifestyle advice (46% UK; 82% Germany). In most instances, the physician was the first to suggest prescribing a PPI (83% UK; 90% Germany). Some patients also reported being aware of PPIs prior to taking them, with approximately one-third of patients (30%) UK; 34% Germany) reporting they became aware through their physician at previous consultations. However, some participants (42% UK; 32% Germany) reported they had "never heard of" PPIs prior to them being prescribed. Interestingly, this was reported by more patients aged over 55 (48% UK; 41% Germany) compared with those aged between 18 and 34 years (18% UK; 9% Germany).

Patients also reported not being provided full information about their treatment upon being prescribed a PPI. Although the majority of patients prescribed a PPI recalled being well informed about what dosage to take (70% UK; 69% Germany) and when to take it (56% UK; 58% Germany), other safety and usage information was not as frequently discussed (Table 3). Duration was not commonly discussed, with not many patients reporting that they were informed about the duration of PPI treatment (22% UK; 38% Germany). A larger proportion of these respondents were current PPI users (74% UK; 62% Germany). There was also very little guidance concerning side effects; very few patients reported being informed about possible side effects or breakthrough symptoms (18% UK; 23% Germany), what to do if side effects occur (19% UK; 18% Germany), or that they may experience rebound symptoms when stopping their PPI (15% UK; 19% Germany). Furthermore, few patients reported being informed about the potential drug-drug interactions with other medications (18% UK; 27% Germany), as well as how long the PPI would need to take effect (17% UK; 30% Germany). A minority of patients reported receiving no information on what to expect from treatment (8% UK; 5% Germany).

#### Patient Experience on Treatment

Patients reported not wanting to stay on PPIs for a long period of time, and around half of patients who received a PPI reported having concerns about long-term treatment (49% UK; 54% Germany) (Figure 1A). Furthermore, approximately one-third of patients were keen to stop

Table 3. Reponses From UK and Germany Patients (UK 372; Germany 194) on Information Provided by the Patient's Doctor Upon	۱
First Being Prescribed a PPI.	

Information patients recalled the doctor providing when first prescribed a PPI	UK (%)	Germany (%)
What dosage to take each day	70	69
When to take the PPI	56	58
How long you should keep taking the PPI	22	38
What to do if you get side effects	19	18
Interactions with other medications	18	27
Possible side effects	18	23
How long for the PPI to take effect	17	30
Possible symptoms once you stop taking PPI	15	19
No information on PPI provided	8	5



Figure 1. (A) Proportion of current and previous PPI users (358 UK; 181 Germany) that agree with the statement "I have concerns about using a PPI long term." (B) Length of time of continuous PPI use reported by all patients (372 UK; 194 Germany).

taking their PPI (37% UK; 32% Germany). Despite this, more than half of patients reported they have been taking a PPI for 1 year or more (64% UK; 50% Germany) (Figure 1B), and this was reported more commonly among PPI users aged over 55 (78% UK; 62% Germany). A smaller proportion of patients (19% UK; 28% Germany) reported having taken their PPI for 2 months or less.

Most patients prescribed PPIs reported either not knowing how long they would be taking their PPI for, or expected to be taking their PPI for over 3 months (88% UK; 80% Germany). 41% of UK and 48% of German patients stated "don't know" when asked for how long they expected to be



**Figure 2.** (A) Proportion of responses from current PPI users (307 UK; 139 Germany) to the question "How long are you expecting to be taking a PPI for?" (B) Frequency of reflux symptoms experienced by patients (358 UK; 181 Germany) whilst taking a PPI.

taking their PPI. Many patients (47% UK; 32% Germany) also reported that they expected to be taking their PPI for 3 months or more (Figure 2A). Of those who had already been taking their PPI for more than 1 year, 52% of UK and 26% of German patients reported they expected to continue taking their PPI for more than 1 year, and 42% and 64% of UK and German patients, respectively, were unclear about the duration of treatment.

Additionally, the majority of patients (66% UK; 80% Germany) reported experiencing breakthrough symptoms whilst taking PPIs. More than a quarter of these patients

(38% UK; 28% Germany) reported experiencing bothersome symptoms once a week or more (Figure 2B), with acid reflux (54%) being the most frequent symptom reported by UK patients.

## Patient Experience When Stopping PPI Therapy

In both countries, the small number of previous PPI users who had stopped taking their PPI (n=65 UK; n=55Germany) did so abruptly (49% UK; 44% Germany) or in a stepwise manner (51% UK; 56% Germany). Of these patients who reduced PPI treatment stepwise few reported reducing their dose (18% UK; 29% Germany); instead reducing PPI frequency was more commonly reported by these patients (35% UK; 33% Germany). The top 3 reasons for stopping treatment by previous PPI users for reflux were reported as not wanting to rely on medication (27% UK; 26% Germany), finishing the course of treatment (25% UK; 24% Germany), and because the doctor recommended stopping treatment (25% UK; 33% Germany). Furthermore, in the population of previous PPI users around half reported a return of symptoms when their PPI was stopped (n=35, 54% UK; n=29, 53% Germany). These symptoms were reported to return within a week in nearly half of these respondents (49% UK; 45% Germany). Additionally, around a quarter of patients (20% UK; 28% Germany) reported experiencing more severe symptoms compared with before taking a PPI. However, most patients reported the symptoms to be either no different (31% UK; 34% Germany) or slightly better (26% UK; 24% Germany).

## Discussion

The results of this study demonstrate the patient-reported variability in treatment and highlight that patient-reported duration of PPI use differs from the standard guidance. Appropriate reflux management involves the stepwise use of lifestyle advice, non-systemic therapy, and PPIs. Approximately 1 in 5 patients had not tried an OTC medication before consulting their physician, who in most cases was the first to recommend a PPI. Although patients reported not wanting to remain on PPIs for prolonged periods, a substantial proportion of patients reported that the expected duration of therapy was not discussed in either the UK or Germany. This was recalled by more patients currently on PPIs rather than previous users of PPIs. As a result, at least 8 in 10 patients did not know how long they would be taking a PPI for and anticipated long-term treatment—a view which does not appear to be widely challenged by physicians. There was also a discrepancy between the UK and Germany in PPI prescribing practice-more patients in Germany reported being well-informed at first consultation with their doctor than in the UK.

An important strength of this study is the patient insight into PPI prescribing practice, which has rarely been a focus in previous research, and demonstrates how important it is for patients to be informed of their medication when starting treatment. A limitation of this study was that it explored patient recall of PPI experience on initiation and use thereafter. Although this questionnaire methodology is appropriate as an insights tool, it is not a validated patient-reported outcome (PRO) measure, and hence future research is warranted using a validated PRO tool. Given that the sample in this study comprised internet users, this may also not give a true representation of the wider population demographic of PPI users. There were disproportionately more female respondents than male respondents in this survey; however, previous studies have found women were more likely to seek health information online than men.<sup>24</sup>

To raise awareness of the appropriate use of prescribing and discontinuing PPIs, education programs combined with guideline-recommended non-systemic therapies<sup>5</sup> for the management of rebound symptoms could be implemented. This would help patients reduce or discontinue their PPI and reduce potential risks associated with long-term PPI therapy. For example, a previous study conducted in the UK found that 3 out of 4 patients who entered the nurse-led Dyspepsia Therapy Review and Education Programme (DTREP) achieved a sustained reduction or complete discontinuation of PPIs using alginate as a short-term rescue therapy to overcome symptoms arising from rebound acid hypersecretion (RAHS) when coming off of PPIs.2 A 49% reduction in PPI prescribing over the 1-year review period was found, resulting in significant cost savings.<sup>2</sup> Relatively simple interventions such as the DTREP are 1 way in which to tackle the overuse of PPIs, as well as encouraging patients to gain a better understanding of their own care. Despite the National Institute for Health and Care (NICE) guidelines having clear recommendations on the appropriate prescribing of PPIs, UK practitioners have shown poor guideline adherence based on patient recall in this study, in line with previous findings showing little change in PPI prescribing patterns following the 2014 NICE guidelines.<sup>5,25</sup>

This study highlights the lack of awareness and understanding of PPI treatment by patients, in part due to the lack of information given by physicians at PPI treatment initiation, as reported by past and present PPI users, and non-compliance with guidelines, based on patient experience with the current PPI-prescription pathway. Current PPI users should be more aware that PPI treatment does not need to be indefinite and be informed of the potential risks of inappropriate long-term use and stepwise approach for discontinuation. The challenge faced by some patients in trying to reduce their PPI treatment is potentially exacerbated by the rebound symptoms experienced upon PPI discontinuation. The increase in gastric acid secretion to above pre-treatment levels after PPI therapy has been discontinued, known as RAHS, is believed to contribute to the difficulty in stopping treatment, as well as the increase in long-term PPI use in patients with no appropriate indication.<sup>26</sup> In our study, less than one-fifth of patients reported being informed about possible side effects or breakthrough symptoms when stopping their PPI. However, almost three-quarters of patients reported experiencing breakthrough symptoms after discontinuing treatment, with approximately one-third of these patients having reported experiencing symptoms as frequently as once a week. This lack of information provided to patients upon treatment initiation could be a contributing factor toward patients staying on PPIs for longer than necessary.

## Conclusions

The prolonged use of PPIs reported by patients in this study presents a barrier to appropriate reflux management. The current treatment and prescription approach of PPIs, based on our findings from patient-reported experience, varies considerably to the standard guidance. Despite patients reporting not wanting to stay on long-term PPI therapy, the results of this study suggest this patient view may not be widely taken into consideration by physicians, as demonstrated by the ease in which PPIs are so readily prescribed for GORD.

## Acknowledgments

Medical writing support was provided by Samantha Brick, Elements Communications Ltd, and funded by Reckitt Benckiser.

## **Author Contributions**

KP collated results, completed analysis, and reviewed the manuscript. NP came up with the study, oversaw the study, and reviewed the manuscript. JG devised the study, developed the survey with a marketing agency, oversaw the study, and reviewed the manuscript. CC came up with the study and reviewed the manuscript. A marketing agency devised the study, executed the study, and performed the analysis.

#### **Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was funded Reckitt Benckiser.

## **Ethics Approval**

Ethics approval was not sought for this study, as it was a surveybased recall study.

#### Supplemental Material

Supplemental material for this article is available online.

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