

## Evaluating how the use of patient information leaflets tailored to a given condition improve health outcomes

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### Abstract

Patient information leaflets (PILs) have been widely used over time as a way to give patients governance over their own health. As information becomes more accessible, there is an increased risk of unreliable information being available to the public. This, combined with the limited consultation time in the clinical setting, can cause misguidance and misunderstanding amongst patients. PILs rectify this by providing credibly sourced information to be used outside of the clinical setting. This good-quality information educates and enables patients to make autonomous decisions with the guidance of their physician. However, PILs have been shown to be counterproductive by burdening patients with too much information, as well as altering outcomes in low literacy patient groups. Thus, physicians should evaluate the use of PILs depending on a patient's individual circumstance so as to ensure their effectiveness in improving health outcomes.

### Abbreviations

PIL - Patient information leaflet

### Introduction

In recent years, there has been a push to move away from a system overseen by paternalism and towards endorsing shared decision-making. Under the guidance of clinicians, patients are becoming more involved in their own medical care, being provided with imperative information that aids their understanding of a given condition.<sup>1,2</sup> The GMC's guidance on consent highlights the importance of working in partnership with patients.<sup>3</sup> The delivery of this information should be

fully comprehensible and appropriate to that of the patient's needs or wants, whether that be by advocacy services, patient information leaflets (PILs), patient programmes or support groups.<sup>2,3</sup>

*PILs are an integral tool that assist patients in making these informed decisions,<sup>4</sup> passing on more power and control to the patient.*

This makes patient engagement crucial for exercising autonomy.<sup>5</sup> However, questions are being raised as to whether PILs improve health outcomes in patients, such as, do PILs lead to neglect of marginalised subgroups of individuals, like those who are illiterate? This article will, therefore, evaluate the advantages and disadvantages of using PILs in clinical practice.

### The benefits of PILs

Clearly constructed PILs used as an adjunct to consultations have shown to improve the understanding of a condition by patients,<sup>6</sup> and this can satisfy a patient's desire to be better informed about their health. Following on from this, a meta-analysis found that PILs contribute to better health outcomes in well informed patients.<sup>7</sup> For example, multiple studies observed positive effects on increased knowledge and satisfaction of patients. Using this transparent sharing of patient information has been shown to diminish patient anxiety.<sup>6,7</sup> A study by Kenny *et al* observed how successful information leaflets were in educating patients on prescription medications.<sup>6</sup> It was found that the group of patients who received leaflets on their prescription medication were more satisfied than those who did

not. Regardless, 97% of patients thought PILs accompanied with prescription medication were a good idea. In addition, the use of PILs in the treatment of patients with rheumatoid arthritis demonstrated reduced rates of depression and pain, suggesting improvement in both physical and mental health domains. This provides a reason to link PILs to better health outcomes.

Sustersic *et al* conducted a study to analyse the impact of PILs on doctor–patient communication in the context of acute conditions presented to two emergency departments in France. It was discovered that PILs improved doctor–patient communication, patient satisfaction scores relating to healthcare professionals, and promoted good medical practice amongst doctors.<sup>4</sup> In the PIL intervention group, more physicians carried out investigations in practice, such as examinations and laboratory analyses, and there was a reduced number of drug prescriptions. It is arguable that this may be the result of PILs improving the dialogue structure between patients and doctors, and PILs acting as a firm reminder for physicians to monitor their drug prescribing.

*Thus, PILs can augment patient outcomes through educating both patients and doctors on better medical practice.*

PILs used in consultation have also been shown to improve adherence to advice and medication.<sup>7</sup> With the implementation of PILs, it was found that there were fewer consecutive visits from patients after initial consultation. For example, Sustersic *et al*'s study of patients with lower back pain showed that information leaflets supported these patients by improving their confidence and adherence to guidance.<sup>7</sup> Consequently, more of the patients were found to apply the information provided within the leaflet, including the recommended exercises, to aid their lower back pain.

As early as 1972, physicians have faced the on-going issue of patients forgetting or misinterpreting the information discussed during a consultation.<sup>6</sup> It is common for patients to feel overwhelmed by the vast amount of information given to them by clinicians and this creates a stressful environment. Unsurprisingly, this can lead to patients struggling to retain the information given outside of the clinical setting.<sup>2,6</sup> Studies have shown an increase, from 20% to 50%, in patients' abilities to recall the information given to them by physicians when a written or visual input is introduced.<sup>6</sup> Even though verbal advice may be deemed adequate, additional forms of educational material, such as leaflets, stand as the most commonly used way of relaying health information.<sup>6</sup> The written information acts to reinforce the discussion during consultation.

As information becomes more accessible via the internet, patient information can be wrongly construed. PILs can be introduced to hamper the number of patients relying on these inaccurate online sources of information. The content of PILs is constructed using evidence-based knowledge. Thus, patients who use PILs are more likely to have a core understanding of information from these trusted sources.<sup>8</sup> In educating the patient, patients can be given a core framework of knowledge, enabling them to judge the reliability/quality of resources found online and make their own informed choices when it comes to applying medical information.

Time restraints on consultations place increasing onus on clinicians to provide information outside of the clinical setting.<sup>5</sup> PILs seem most appropriate to hand to patients when consultations are restricted to a mere ten minutes. Having a PIL breaks up the amount of verbal communication required and reinforces the discussion during consultation. Patients are also able to take away the PIL, refresh their understanding of what was discussed with their physician and review their knowledge of the condition. Sustersic *et al* (2019) explain that within the quick-paced environment of emergency departments, there is little time for doctors to clearly provide information to

patients.<sup>4</sup> Thus, PILs are valued in this context, as the information given during consultation is more likely to be respected and retained, even after the patient has returned home.

*Furthermore, patients may be prompted to question their healthcare more when a PIL is introduced.*

Moreover, an emergency department environment, such as that used in Sustersic *et al*'s study, can be stressful for a patient. PILs given in an emergency setting could encourage patients to adhere to their doctors' advice, so that they do not find themselves in this high-pressure environment again; hence, patient adherence to the guidance given in an emergency setting could be higher than that seen in primary care.

## The limitations of PILs

Clinicians are able to gauge a patient's level of understanding and determine how to best adapt their use of terminology to explain a given condition.<sup>8</sup> PILs, however, have no such ability to adjust the information given to suit the patient's knowledge. Thus, the application of PILs in educating individuals with low literacy is limited greatly, as these individuals may lack the ability to read simple written information.<sup>5,9</sup>

*Amounting to 20% of the UK adult population, individuals with low literacy are an important group to consider when creating informative PILs.*

There are a range of patient demographics that make an individual more vulnerable to low health literacy, such as old age, chronic illness or disability, low socioeconomic status, being of ethnic minority and reduced language proficiency.<sup>5</sup> In Herber *et al*'s study, patients with a migration background were described to heavily rely on their practitioners to grasp health information, regardless of whether a PIL was provided.<sup>10</sup> Thus, encouraging patient engagement via PILs is massively hindered in these already disadvantaged patients. To be beneficial to low literacy audiences, PILs should be presented in a format that is clear and in plain English.<sup>9</sup> They also should include information that signposts patients to other sources, such as online websites that could aid in the understanding of the PILs and, therefore, help to reduce the inequalities between patients with low and high health literacy.

Since some patients may not be able to read PILs, PILs alone are not enough to encourage patient education. PILs require some level of patient input; primarily, it is essential for patients to be motivated enough to read and understand the PIL given to them to result in beneficial changes.<sup>6,7</sup> Some patients disregard PILs because they do not wish to know more about their condition. In addition, PILs that focus on general health were found to be more neglected by patients than tailored PILs that were given to a patient for a specific condition.<sup>6</sup> This could imply that PILs are more effective when there is a level of tailoring to suit the patient's individual needs.

As previously mentioned, some studies have indicated improved doctor–patient communication following use of PILs.<sup>4</sup> However, in their 2019 study, Sustersic *et al* observed that patients that were not given PILs demonstrated similar adherence to advice given by physicians as those given PILs.<sup>4</sup> One possible explanation for such a finding could be put down to an overload of information given to patients who received both oral and written forms of communication. However, PILs have been shown to mitigate information overload and, therefore, further studies are required to investigate this area.

## Conclusion

The effectiveness of PILs is dependent on how much a patient wishes to know about their diagnosis. In other words, PILs cannot be used uniformly for every patient. When used, however, there is evidence of improved health outcomes. Employment of PILs in consultation should be at the physician's discretion and dependant on whether they believe their use is suitable for the situation and the patient's individual needs or desires.

It may not be appropriate to use PILs to educate minority groups, such as those with special needs or of lower health literacy. Adopting an alternative and more accommodating method of delivery of information may be more beneficial than PILs for these individuals.

PILs also require consistency in terms of quality of information and content. There is evidence for varying information in PILs across different hospital trusts, with some containing information deemed inadequate when compared to others.<sup>9</sup> The absence of national set standards to rectify these faults perpetuates the improper use of PILs in clinical settings. Consequently, further studies should be conducted to confirm whether PILs, on a national scale, are at a suitable standard.

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