


# Hospital practices for the implementation of patient partnership in a multi-national European region

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**Background:** The extent to which patients are involved in their care can be influenced by hospital policies and interventions. Nevertheless, the implementation of patient participation and involvement (PPI) at the organisational (meso) level has rarely been assessed systematically. The aim of this study was to assess the occurrence of PPI practises in hospitals in Belgium, France, Germany and Luxembourg and to analyze if, and to what extent, the hospital vision and the presence of a patient committee influence the implementation of PPI practises. **Methods:** A cross-sectional study was carried out using an online questionnaire in hospitals in the border regions of the four countries. The data were analyzed for differences between regions and the maturity of PPI development. **Results:** Full responses were obtained from 64 hospitals. A wide range of practices were observed, the degree of maturity was mixed. A majority of hospitals promoted patient partnership in the hospital's philosophy of care statement. However, the implementation of specific interventions for PPI was not found uniformly and differences could be observed between the countries. **Conclusions:** Hospitals in the region seem to be motivated to include patients more fully, however, implementation of PPI interventions seems incomplete and only partially integrated into the general functioning of the hospitals. The implementation of the concept seems to be more mature in the franco-phone part of the region perhaps due, in part, to a more favourable political context.

## Introduction

Patient participation and involvement (PPI) is a key component of high-quality healthcare.<sup>1,2</sup> A growing body of evidence shows that involving patients in the healthcare system leads to positive outcomes<sup>3</sup> such as higher patient satisfaction,<sup>4</sup> better quality of care<sup>5</sup> and better health and costs outcomes.<sup>6</sup> There is agreement that, to be effective PPI should be present in primary, secondary and tertiary care and at all three levels of the healthcare system at micro level (direct care), meso (institutional governance) and macro (health policy).<sup>7,8</sup> The degree of PPI present in hospitals (secondary and tertiary care) has rarely been assessed systematically<sup>3</sup> and we found no evidence that this has been done in the frontier regions of Belgium, France, Germany and Luxembourg (known as the Greater Region, hereafter GR). The study presented in this paper focuses on PPI in hospitals in the GR.

Many different concepts have emerged to describe the movement around PPI, among them: patient-centred care,<sup>9</sup> patient empowerment,<sup>10,11</sup> patient participation,<sup>1,12,13</sup> and patient partnership.<sup>7,14–16</sup> Correspondingly, numerous activities have

been developed to try to encourage greater patient participation in hospitals.<sup>17,18</sup> These range from including patients in decision making about hospital management,<sup>19</sup> developing decision aids to encourage shared decision making,<sup>20</sup> patient access to medical records,<sup>21</sup> to patient participation in healthcare professional training.<sup>22</sup> Though these concepts differ<sup>10,11,13</sup> in essence, the patient's experiential knowledge is increasingly considered complementary to the knowledge of healthcare practitioners and administrators of healthcare institutions.<sup>11,15,23,24</sup>

PPI could be considered to be well established in countries such as UK, Australia, The Netherlands, Canada and USA.<sup>25</sup> However, it seems other countries have not embraced the concept to such a degree.<sup>25,26</sup> Given the benefits of PPI and the ethical and democratic arguments to reduce paternalism in healthcare it is important that implementation is spread widely.

The aim of this study was to assess the existence of practices related to PPI at the meso level of hospitals in the region. In addition, we explored two hypotheses: (i) that hospitals with a higher degree of PPI in the hospital vision had a greater uptake of other interventions regarding PPI practices and (ii) that the presence of a

patient committee was associated with a higher number of PPI practices.

## Methods

A cross-sectional study was performed using an online questionnaire. Hospitals in the border regions of Belgium (Wallonia), France (Lorraine), Germany (Rhineland–Palatinate/Saarland) and Luxembourg were invited to participate. The study was part of an interregional project named APPS (Approche Patient Partenaire de soins—Patient Partner Approach in Healthcare).<sup>27</sup>

### Questionnaire development

The questionnaire was predominantly based upon two theoretical frameworks: the Carmen model of Patient and Family engagement<sup>8</sup> and the Montreal model of Patient Partnership by Pomey et al.<sup>14</sup> Existing and validated questions were used where possible.<sup>3,28–30</sup> The final questionnaire had six sections: general hospital characteristics, hospital vision or mission, direct care, organisational design, education and research (see Annexes 1 and 2 for further information about the development of the questionnaire and the full questionnaire in [Supplementary data](#)).

To assess the content, consistency and clarity, diverse members of the project team reviewed the questionnaire. Additionally, a representative from the European Patients Forum gave feedback towards the end of the process. The final questionnaire was tested in a pilot study with healthcare experts in each region. The ethics committee of the University of Liège gave its agreement on 26 September 2017 under reference number 2017/232.

### Target population

The questionnaire was designed for completion by members of hospital administration such as medical directors, nursing directors, CEOs or members of the quality management team. The survey targeted all acute care hospitals in the territory of the GR excluding psychiatric institutions and convalescent homes.

### Data collection and recruitment

Invitation letters were sent by post or email (one invitation per hospital) to the medical director, CEOs or quality managers (depending on the region) of 126 hospitals. Invitations were followed by an email providing a personalised link to the online questionnaire. Reminders to non-responders were done by email and phone. The concept of patient partnership was mentioned in the invitation letter and the front page of the survey but not discussed in detail to avoid influencing the answers given.

Online data collection was carried out between 19 January 2018 and 24 April 2018. The programme EFS-Survey from QuestBack was used to host the questionnaire and centralise the data.

### Data analysis

We tested sample representativeness by comparing responding and non-responding hospitals using Pearson's chi-squared tests. We tested on region, hospital size, location (rural vs. urban) and funding source. Differences between regions were tested with a descriptive analysis and Fisher's exact test. To test the relationship between hospital size, presence or absence of PPI in the hospital vision and the existence of a patient committee with the degree of PPI practices in the respective hospital, Pearson's chi-squared tests and Fisher's exact tests were carried out.

To assess the degree of patient participation in the hospital vision, the questions 'Does the organisation's philosophy of care statement promote partnerships with the patients it serves?' and 'Is patient partnership integrated into the strategic plan of the hospital?' were combined. If both questions were affirmed PPI in hospital vision

**Table 1** Comparison of the characteristics of responding and non-responding hospitals<sup>a</sup>

Characteristics	Non-respondents, n (%)	Respondents, n (%)	All eligible, n (%)	P value
N	62 (100.0)	64 (100.0)	126 (100.0)	
Region				0.124
Germany	25 (43.9)	24 (39.3)	49 (41.5)	
France	28 (49.1)	28 (45.9)	56 (47.5)	
Belgium	4 (7.0)	9 (14.8)	11 (11.0)	
Beds (category)				0.153
<300	36 (64.3)	34 (55.7)	70 (59.8)	
300–599	15 (26.8)	15 (24.6)	30 (25.6)	
600+	5 (8.9)	12 (19.7)	17 (14.5)	
Location				0.545
Rural	27 (48.2)	29 (47.5)	56 (47.9)	
Urban	29 (51.8)	32 (52.5)	61 (52.1)	
Ownership				0.439
Public	24 (44.4)	23 (37.7)	47 (40.9)	
Non-profit	21 (38.9)	31 (50.8)	52 (45.2)	
Private	9 (16.7)	7 (11.5)	16 (13.9)	

a: Due to the small number of Luxembourgish hospitals and the challenge to maintain anonymity, we could not include respondents from Luxembourg in the analysis displayed in [table 1](#).

was considered to be 'fully present'. If one of the questions was negated, PPI in hospital vision was considered to be 'present to some extent'. If both questions were negated, we considered that there was 'no PPI in hospital vision'.

The selection of variables for comparison was limited to non-filtered questions based on theoretical assumptions and on the n of each question.

Due to the small sample size, only descriptive analysis and univariate statistical tests were done. All analysis was done using IBM SPSS Statistics 25. Tests were two-sided calculated to an alpha equal to 0.05.

## Results

Of the 126 hospitals surveyed, 64 (50.8%) fully responded: 9 out of 13 from Belgium (69.2%), 28 out of 56 from France (50.0%), 24 out of 49 from Germany (49.0%) and 3 out of 8 from Luxembourg (37.5%). Only hospitals that had completed the questionnaire until the last page were included in the analysis.

There were no significant differences regarding hospital characteristics ([table 1](#)). About 54% of respondents were hospital directors and ~36% members of quality management. The remaining surveys were completed by other hospital staff.

[Table 2](#) displays the results of a selection of variables from each section of the questionnaire. Since only a quarter of the hospitals stated that they participate in research, this aspect is not discussed in this paper.

### Hospital vision and mission

When asked whether patient partnership was promoted in the hospital's philosophy of care statement 83% of all hospitals said this was the case. About 27% said their philosophy of care statement fully promoted partnership with the patients it serves. In order to assess the degree of implementation, the next question asked if patient partnership was integrated into the strategic plan of the hospital. Half of the hospitals in the sample said that this was the case. There was a statistically significant difference between the regions, the lowest rate was in Germany, 25% of the participants responded yes to this question whereas in France 74% responded yes.

**Table 2** Comparison of the differences between the regions of Germany, France, Belgium and Luxembourg

Question	DE, n (%)	FR, n (%)	BE, n (%)	LUX, n (%)	Total, n (%)	P value <sup>a</sup>
<b>Hospital vision or mission</b>						
Does the organisation's philosophy of care statement promote partnerships with the patients it serves?						0.559
Yes	20 (83.3)	23 (85.2)	6 (66.7)	3 (100.0)	52 (82.5)	
Is patient partnership integrated into the strategic plan of the hospital?						0.003
Yes	6 (25.0)	20 (74.1)	5 (55.6)	1 (33.3)	32 (50.8)	
<b>Direct care</b>						
Are healthcare users routinely asked to evaluate the quality of HCP/professional communication?						0.118
Yes	21 (95.5)	19 (73.1)	7 (77.8)	2 (66.7)	49 (81.7)	
Are patients included in production of patient resources?						0.021
Yes	1 (4.3)	10 (38.5)	2 (22.2)	0 (0.0)	13 (21.3)	
Does the hospital provide training for staff on how to communicate with patients?						0.926
Yes	19 (79.2)	19 (73.1)	7 (77.8)	3 (100.0)	48 (77.4)	
Are patients provided with decision aids for various health conditions?						0.029
Yes	18 (78.3)	18 (78.3)	5 (55.6)	0 (0.0)	41 (70.7)	
Involving patients in decision making and care is a priority						0.506
Yes	16 (69.6)	17 (81.0)	5 (55.6)	2 (66.7)	40 (71.4)	
Are there formal training programmes for hospital staff on partnering with patients in care plan decision making?						1.000
Yes	4 (17.4)	5 (21.7)	2 (22.2)	0 (0.0)	11 (19.0)	
Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?						0.002
Yes	1 (4.3)	10 (5)	4 (44.4)	0 (0.0)	15 (27.3)	
<b>Organisational design</b>						
Does the hospital have a patient committee?						0.003
Yes	1 (4.3)	11 (47.8)	2 (22.2)	0 (0.0)	14 (24.1)	
Does the hospital have a policy or guidelines that facilitate unrestricted access, 24 h day <sup>-1</sup> , to hospitalised patients by family and other partners in care according to patient preference?						0.190
Yes	15 (68.2)	10 (43.5)	3 (33.3)	2 (66.7)	30 (52.6)	
Access to medical records						0.231
Unrestricted access	16 (76.2)	14 (60.9)	4 (44.4)	1 (33.3)	35 (62.5)	
Is information given routinely to patients on how to access their medical records?						0.001
Yes	7 (35.0)	16 (94.1)	4 (80.0)	1 (50.0)	28 (63.6)	
Are patients normally involved in forms of quality improvement in the hospital?						0.002
Yes	9 (39.1)	21 (87.5)	6 (66.7)	1 (33.3)	37 (62.7)	
<b>Education</b>						
Does the hospital have patient experts, trained to work with other patients as part of patient education?						0.008
Yes	2 (8.7)	12 (48.0)	1 (11.1)	0 (0.0)	15 (25.0)	
Do patients participate in the training of health care professionals in your hospital?						0.460
Yes	0 (0.0)	2 (8.0)	1 (12.5)	0 (0.0)	3 (5.1)	

a: Fisher's exact.

### Direct care

Most of the hospitals surveyed (81.7%) stated that patients are routinely asked to evaluate the quality of communication between health care professionals and patients. The majority of hospitals (77.4%) also said that they provide training for hospital staff in how to communicate with patients. These include courses on how to encourage patients to ask questions, give their opinions and express concerns, approaches for eliciting patients' values, goals and needs and how to create opportunities to hear from patients about their perspective of the care experience at the hospital.

Overall, patients are included in the production of patient resources in 21% of the surveyed hospitals. There is a significant difference between Germany, Belgium and France. Where patients are included, they mostly review the resources produced (53.8%).

Regarding shared decision making, 71.4% of all hospitals said that involving patients in decision making and care is a priority. About three-quarters also said that it is supported and documented by

practice teams. About 18.9% stated that the practice teams are trained in decision-making techniques.

In most hospitals, patients are provided with decision aids for some diseases (70.7%). One in five hospitals stated that there are formal training programmes provided to hospital staff on partnering with patients in the care plan decision-making process.

Most hospitals (69%) do not have a policy to encourage greater participation of patients at interdisciplinary meetings. Hospitals in France seem to be more active in this regard. About 43.5% ( $n = 10$ ) of the hospitals there said they encourage greater participation of patients at interdisciplinary meetings, whereas in Germany, only one hospital said so.

### Organisational design

Patient committees are not a commonly established practice in the GR. Of the hospitals surveyed, 24.1% said they have a patient committee. By patient committees, we refer to all types of institutionalised associations where patients can participate in the hospital

**Table 3** Correlation between hospital governance and PPI practices

Question	PP in hospital vision or mission				P value	Fisher's exact
	No, n (%)	To some extent, n (%)	Yes, n (%)	Total, n (%)		
Are healthcare users regularly asked to evaluate the quality of HCP/professional communication?					0.012	0.029
Yes	5 (50.0)	17 (89.5)	25 (89.3)	47 (82.5)		
Are patients included in production of patient resources?					0.039	0.047
Yes	0 (0.0)	3 (13.6)	10 (34.5)	13 (21.3)		
Does the hospital provide training for staff on how to communicate with patients?					0.026	0.026
Yes	5 (50.0)	16 (72.7)	27 (90.0)	48 (77.4)		
Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?					0.014	0.017
Yes	0 (0.0)	3 (15.0)	12 (44.4)	15 (27.3)		

**Table 4** Differences dependent upon the presence of a patient committee

Question	No, n (%)	Yes, n (%)	Total, n (%)	P value	Fisher's exact
Are patients included in production of patient resources?				0.002	0.005
Yes	5 (11.6)	7 (50.0)	12 (21.1)		
Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?				0.001	0.001
Yes	7 (16.3)	8 (66.7)	15 (27.3)		
Are patients normally involved in forms of quality improvement in the hospital?				0.009	0.010
Yes	23 (52.3)	12 (92.3)	35 (61.4)		

governance, to meet the different forms of groupings in the GR. There was a statistically significant difference between the regions, 47% ( $n = 11$ ) of the French hospitals had a patient committee compared to one hospital in the German region. Two hospitals state that over 75% of the committees' members are patients or family members of patients. In most cases, the quota of actual patients in the committee is <25%.

Regarding the involvement of family members and friends, more than half of the hospitals (55.2%) stated that they have written policies enabling patients to identify preferences concerning the active involvement of family members or other individuals in their care process. About half (52.6%) of the questioned hospitals have a policy or guidelines to facilitate unrestricted 24h a day access to hospitalised patients by family members or other care partners.

Options of unrestricted access to medical records are given by most hospitals questioned and one-third of those states that patients are systematically informed about how they can access their medical record. In contrast to France (94%) and Belgium (80%), 35% of the hospitals in Germany stated that they routinely inform patients about how to access their records, a statistically significant difference. One-fifth (18%) of all surveyed hospitals do not allow their patients access, however, only two provide an online platform to access medical records. None of the questioned hospitals gives patients an opportunity to edit their medical records.

The inclusion of patients in feedback systems to improve the quality management of hospitals seems to be relatively common practice in the region 62.7% overall, however, statistically significant differences exist between the regions, the highest percentage was found in France 87.5%.

### Education

The practice of patient experts seems to be relatively uncommon in hospitals in the GR. Of the surveyed hospitals, 25% reported that they have patient experts, (trained to work with other patients as part of patient education for chronic diseases) the majority for diabetes and cancer. In Belgium, Germany and Luxembourg, the use of

patient experts appears to be negligible. In France, 48% of the hospitals surveyed said they use patient experts. Three of the hospitals (two in France and one in Belgium) employ patients in the training of health care professionals as educators or content developers.

### Correlation between hospital governance and PPI practices

Hypothesis one was that hospitals promoting partnerships with patients in the philosophy of care and their strategic plan have a greater 'uptake' of other interventions regarding PPI practices. This seems to be the case for a few practices (table 3).

Overall, half of the hospitals surveyed promote PPI in their philosophy of care statement and have the concept integrated into their strategic plan. These hospitals are statistically more likely to have patients evaluate the quality of HCP/patient communication and to include them in the production of patient resources. They are also more likely and to provide training for staff on how to communicate with patients and have a policy to encourage greater participation of patients at interdisciplinary meetings.

### Correlation between the presence of a patient committee and PPI practices

Hypothesis two was that the presence of a patient committee was associated with implementation of a higher number of other PPI practices (table 4). Hospitals with a patient committee more often state that they include patients in the production of patient resources as well as in forms of quality improvement in the hospital. Those hospitals also more often have policies to encourage greater participation of patients at interdisciplinary meetings than hospitals without a patient committee.

## Discussion

This study reports that a wide range of institutional practices supporting PPI can be found in hospitals in the GR. Among these

hospitals, the degree of implementation varies noticeably and there seem to be significant differences between the four countries. In general, French hospitals seem to be more advanced in the implementation of PPI than Belgian, German or Luxembourgish hospitals in the GR.

Most of the hospitals appear to have at least a degree of organisational leadership for PPI, though the process of implementation is still immature. Of the 31 hospitals stating that patient partnership was integrated into the strategic plan of the hospital, only 9 said that the relevant dimension of the strategic plan was in place in all units. Nevertheless, the presence of PPI in the philosophy of care and strategic plan of the hospital would contribute to a 'receptive context' for PPI; an important facilitator for implementation.<sup>31</sup> We could infer, therefore, that the process of implementation seems to have started, and important leadership elements are present.<sup>32</sup>

There was some evidence that action for PPI in the region is more centred around direct encounters with patients. For example, shared decision making was declared to be a priority for the majority (71%) of hospitals in the region, however, training opportunities for hospital staff seemed to be limited. Training courses for practitioners, offered by institutions, are an important facilitator of shared decision making and have been shown to be determinants of a facilitating organisational context.<sup>33,34</sup> Thus, while motivation towards shared decision making appears to exist in the region its application, including, embracing the full potential of the role of patients is incomplete. This reflects the findings of Härter et al.<sup>35</sup> and Moumjid et al.<sup>36</sup>

A striking difference between the regions was the limited existence of patient committees, much more common in France than the other countries and far from uniformly in place in the GR. Although simply having a patient committee does not necessarily ensure the hospital is listening to patient's views in a serious and careful manner. Its utility and power is dependent upon how it functions and, more importantly, how it is 'designed' to function.<sup>37</sup> Furthermore, the representativeness of the patient committee is important.<sup>38</sup> For most patient committees in our sample, only 25% (or less) of the members were actually patients. Nevertheless, our results point to a correlation between the presence of a patient committee and other activities for PPI indicating that the existence of a patient committee is probably still preferable to not having one at all, with the caveat that this is a complex issue.

In general, it can be stated that PPI is more common and shows a more mature implementation in the francophone areas of the GR. The different health systems and the country-specific associated government regulations may explain these differences. In France, the movement has been gaining momentum resulting in legislation stating that patients should be actors in their healthcare decisions and real 'partners' in the relationship with healthcare professionals.<sup>37</sup>

In Belgium, the movement towards greater patient participation has been evolving, albeit more slowly than in France. Since the patient's right act in 2002 patients are now present on committees of different organisations such as the Federal Agency for Medicines and Health Products (INAMI), and the Belgian Health Knowledge Centre (KCE) as well as the regional organisation L'Agence pour une vie de qualité (AVIQ).<sup>39</sup>

In Germany, on the other hand, progress seems to be slower, legislation supporting patient's rights was not enacted until 2013 based on an EU Directive on Patients' Rights in Cross-Border Healthcare. Different intervention strategies have been developed but the main focus remained rather on the widening of access to, as well as digitalisation of, information for patients than on real patient participation or partnership.<sup>36</sup>

In Luxembourg, there has been a slow movement towards patient participation. The ehealth strategy adopted in 2006 aimed to improve information sharing among professionals with an eventual objective to increase the patient's participation in their care moving 'little by little towards a partnership'.<sup>40</sup> The current health strategy

2018–25 refers to the inclusion of patients particularly in the case of rare diseases, however, it lacks detail or specific objectives.<sup>40</sup>

### Limitations

This study had an adequate response rate of 50.8% with a relatively small sample size of 64 hospitals. Though our sample did not differ significantly from the non-responding hospitals, it is not a true random sample so the results cannot be generalised to the statistical population using inferential statistical methods. Nevertheless, we can assume that the response pattern regarding PPI practices in the hospitals tends towards a good representation of the situation in the region.

Cross-sectional surveys reflect snapshots of current preferences, assessments and expectations, which naturally change over time, additionally, the effects and correlations found, merely reflect tendencies. The results may display individual response patterns of the participant which may be biased by their rank or personal knowledge or awareness of certain strategies or practices in their hospital leading to under- or over-reporting. Therefore, we cannot be sure of the extent to which responses correspond to actual practices. It is also possible that the hospitals that responded may have been those that had already embraced more PPI practices. Alternatively, since there tends to be a strong political and normative trend towards more PPI participants may have exaggerated the action taken by their hospitals, meaning that the true presence of PPI is perhaps lower than reported here. All these aspects should be considered carefully when interpreting the data.

Triangulation of the results, checking the existence of interventions in the hospitals and linking these to the data presented in the questionnaire would have been useful. However, given the anonymisation of the data, this was impossible.

Although a representative of the European Patients Forum participated in the elaboration of the questionnaire, regrettably, we could not include patients in the data analysis or interpretation phases of the study. This was due to a lack of budget to appropriately reimburse and recognise the work this would have entailed.

### Further research

The results of this study are explorative and would benefit from further verification, the questionnaire should also be evaluated for validity and reliability.

With regards to our findings, research analyzing the barriers for hospitals to include PPI practices would be helpful to better understand patient partnership at the institutional level. In addition, the role of the external political context and the impact of policies at regional, national and international level on hospital's openness to institutional change would help complete the picture.

The questionnaire was designed in order to make international comparisons between four countries which required finding a balance between posing questions sufficiently specific to the different contexts but broad enough to enable comparisons. Though we used questions from existing surveys as much as possible, the questionnaire has not been validated as a whole. In order to fine-tune the questionnaire, within the constraints described above, a study of inter-rater reliability should be done to assess the way different professional profiles complete the questionnaire. A study assessing validity should also be undertaken to optimise the questionnaire for the European context. Though challenging to undertake, international comparisons of health systems are a vital element of quality assurance and improvement and should be invested in to encourage cross border learning and cooperation.

### Conclusion

This study provides the first overview of the existence and degree of institutional practices related to PPI in hospitals of the GR.



In general, it seems that the implementation of the PPI concept is incomplete and only partially integrated into the general functioning of hospitals in the region. The French regions appear to be more advanced than those situated in Belgium, Germany and Luxembourg indicating scope for cross-border learning and perhaps the role of a more favourable political context. Though, it seems that having a patient committee or including PPI in the strategic plan of the hospital is not enough to fully implement PPI into practice, our findings lead us to the assumption that these actions could be a first step to improve PPI uptake. This emphasises the importance of strengthening the institutional application of PPI on the institutional governance level to improve it on an overall scale and truly involve patients as partners.

## Supplementary data

Supplementary data are available at *EURPUB* online.

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### Key points

- Hospitals can encourage patient participation and involvement with a variety of interventions and institutional practices.
- This comparison of hospitals in four countries (France, Belgium, Germany and Luxembourg) found that implementation of the concept was more mature in the French part of the region
- The presence of a patient committee or including PPI the strategic plan of the hospital may be a first step towards improving PPI in practice.
- A health policy context that encourages greater PPI may improve the adoption of appropriate interventions in hospitals

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