

ARTICLE INFO

Submitted: 05-11-2024

Accepted: 12-10-2025

Online: 31-03-2026

The Consensus of Medical Educators' Perspectives on Patient and Public Involvement in Malaysian Medical Education

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To cite this article: Mohamed AR, Sanip S, Omar MR, Abdul Rahman NF, Mohd Jamil MR, Idris F. The consensus of medical educators' perspectives on patient and public involvement in Malaysian medical education. *Education in Medicine Journal*. 2026;18(1):17–29. <https://doi.org/10.21315/eimj2026.18.1.2>

To link to this article: <https://doi.org/10.21315/eimj2026.18.1.2>

ABSTRACT

Patient and public involvement (PPI) as 'experts with experience' has a significant role within the healthcare system, particularly during the pandemic when direct patient contact was limited. Thus, this study aimed to reach a consensus among Malaysian medical educators on the important characteristics and factors influencing PPI in undergraduate medical education. A Delphi study was conducted on 59 medical educators in a two-round survey using a 25-item questionnaire. Fuzzy-Delphi technique was used to analyse the results from the second-round survey. An item was accepted as a consensus if the threshold value (d) was < 0.2, the consensus percentage (c) was > 75%, and the fuzzy score (fs) was ≥ 0.5 . The medical educators reached a consensus on 16 out of 25 items, comprising PPI activities (4 items), safety measures taken by the faculty (3 items), pressing issues (2 items), motivations for involvement (2 items), the importance of PPI (3 items), and issues with PPI during the pandemic (2 issues). Despite agreeing on most items, the discrepancies in the remaining nine items indicated the need for a cohesive framework to guide PPI in Malaysian medical education.

Keywords: *Patient and public involvement, Undergraduate medical education, Educators, Delphi study, Malaysia*

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INTRODUCTION

Patient and public involvement (PPI) refers to the participation of patients and the public in various aspects of medicine and health, particularly in healthcare services, education, and research (1). This group comprises patients, their carers, and healthy individuals receiving social and health services (2). The PPI represents an active collaboration between researchers and members of the public, patients, and caregivers throughout the research process, with emphasis on the ‘with’ or ‘by’ individuals instead of ‘to’, ‘about’, or ‘for’ them (3). This collaboration aims to align research objectives with the needs and experiences of those affected by the issues at hand, thereby ensuring the relevance and quality of the research outcomes (4, 5).

The PPI initiatives are proactively championed in Europe, particularly in the United Kingdom (UK), and included in Tomorrow’s Doctors, the UK regulatory standards for undergraduate medical education (6). In addition, an advisory group known as INVOLVE was established to monitor and support PPI initiatives in the National Health Service, public health, and social care research (3). This advisory group does not directly manage the educational context, but moderates the outcomes of the initiatives.

The paternalisation of medicine in Southeast Asia (SEA) is significantly influencing the development of the PPI framework. In this region, physicians often assume a dominant role in decision-making, driven by deep trust and respect for the profession. This phenomenon may be perceived as limiting patient autonomy and engagement from the Western ethical lens; thus, inclusive practices such as PPI may enhance patient involvement in their healthcare (7). The need for a PPI framework in SEA is therefore driven by culturally recognised respect for authority and expectations of physicians’ decision-making on patients’ behalf, juxtaposed against the paternalistic model that may not be serving patients’ best interests and the global influence of the Western model of decision-making that encourages patient empowerment (8). Cognizant of the cultural and historical differences between Western and SEA health structures and beliefs, PPI is envisioned to incorporate collaborative decision-making that is culturally responsive and integrative in medical education.

Other factors that underscore the need to develop an optimal PPI framework in medical education include the paternalistic ethos of medicine in SEA countries (9), the need to shift towards a patient-centred approach in healthcare design (3), and the limitations on actual patient contact during the pandemic. Furthermore, educational institutions need to be more socially responsive to changes in healthcare democratisation. The conceptualisation of health and disease has transformed from a predominantly biomedical to a biopsychosocial model of medicine (2), highlighting the importance of patient-centred health management. Patient-centred health suggests that healthcare experts play a significant role in the biomedical aspect, while patients are experts on their experiences and sociocultural backgrounds that influence their health (10).

A specific PPI framework is needed for local and regional implementation, given the many facets of healthcare education that underpin medical education in SEA. Below are notable frameworks designed to integrate PPI throughout the educational processes.

- a. The National Institute for Health and Research (NIHR) Framework: A UK-based framework for health research and education that assists institutions in developing action plans for PPI purposes (11–13).

- b. The Public Involvement Impact Assessment Framework: This framework is designed to evaluate the impacts of PPI initiatives, including the level and efficacy of institutional engagement and communication with patients and the public (14).
- c. The EDGE Tool by the National Co-ordinating Centre for Public Engagement: This framework supports organisations by providing a structured approach to improve PPI efforts (15, 16).
- d. Institution-driven frameworks have been developed to ensure clear embedment for health science training programmes, including curriculum design, assessment, and delivery (17).

In the Malaysian context, the PPI standards in medical education lack clarity and are further perpetuated by a paucity of systematic studies that include stakeholders' perspectives. Most institutions are at Level 3 on the involvement spectrum, where "patient shares his/her experience with students within a faculty-directed curriculum" (18). In addition, each medical institution manages the PPI initiative independently due to the lack of a cohesive implementation guideline. Moreover, differences in opinions on the implementation and impact of PPI exist within the medical education community despite the increasing support. Generally, educators recognise the importance of incorporating patient perspectives into curricula, but implementing this requires standardised frameworks that effectively integrate academic training with real patient experiences (6, 7). Besides, medical education in Malaysia has limited knowledge of prominent issues affecting those on the ground. Therefore, this study aimed to determine the collective opinions of medical educators regarding PPI in Malaysia. The study's findings helped identify prominent issues that warrant consideration and guide the development of a cohesive PPI framework for Malaysian medical education.

METHODS

Study Design

A modified Delphi technique was used in the survey to gather experts' consensus regarding the PPI practices in local medical education. The Delphi technique is a common tool used in empirical studies for problem-solving, idea development, and determining the priorities of specific issues (19). This technique is beneficial for gathering convergent opinions on real-world matters (3). The main principle of the Delphi technique is the use of an iterative process (rounds) to gather multiple views from experts in the selected field, rather than individual views, to enhance the validity of study outcomes (1).

Participants

All participants were briefed about the study and provided their informed consent. Two rounds of consensus gathering were conducted in this study based on 10 constructs identified from the literature (Table 1). In the first round, participants were recruited from the Medical Educators Network and the Malaysian Association of Education in Medical and Health Science. The participants have extensive professional experience in their medical or health science faculties and actively participate in scholarly events organised by their associations. Meanwhile, participants in the second round of the survey were purposively recruited via email from medical faculty administrators and medical and clinical educators from Malaysia's public and private medical schools.

Data Collection

In the first round, open-ended responses were analysed according to Saldana's Coding Manual for Qualitative Researchers (20) and the Thematic Analysis of Qualitative Data: AMEE Guide No. 131 (21). The emerging themes were coded and categorised accordingly, which were then developed into answer options on a 5-point Likert scale in the second round. Table 1 presents the 25 items established from the data gathered in the first round and used in the second round of the Delphi study. The Fuzzy Delphi formula was applied in the quantitative analysis of the second-round responses using Microsoft Excel (Microsoft, USA). The collected data were analysed for the threshold value, the percentage of item consensus, and the fuzzy score. An item was accepted as reaching a consensus when all three criteria were fulfilled (threshold value ≤ 0.2 , consensus percentage $\geq 75\%$, and fuzzy score ≥ 0.5).

Table 1: PPI key aspects identified from the literature and educators' view

No.	Items
	PPI activities at the faculty:*
1.	Teaching & learning*
2.	Assessment*
3.	Student research*
4.	Engagement with patients*
	Measures taken by the faculty to ensure safety:*
5.	Explaining and acquiring consent**
6.	Keeping patient's confidentiality and privacy**
7.	Taking precautionary measures and ensuring good medical care**
8.	Providing adequate monitoring & supervision**
9.	Ensuring patient safety*
10.	Ensuring student and staff safety*
	Pressing issues in PPI:*
11.	Confidentiality and privacy**
12.	Safety and care for the patient**
13.	Honorarium payment**
14.	Acknowledgement of the patient's roles**
15.	Patient's understanding of their roles**
16.	Patient groups having access to information on teaching & learning*
	Motivation for involvement: *
17.	Monetary benefit**
18.	Medical care benefit**
19.	Spirit of volunteerism**
	Importance of PPI:*
20.	Patients and the public are important stakeholders**
21.	Application of knowledge**
22.	Authentic learning resources**
	Issues with PPI during the pandemic:*
23.	Limited availability**
24.	Safety concerns**
25.	PPI alternatives**

Notes: *Construct identified from literature; **Theme identified during round 1

RESULTS

A total of 19 participants were recruited in the first round and 40 in the second round of this Delphi study (Table 2). Most participants were from public medical schools in Malaysia and had diverse roles in the faculty (clinical educators, medical educationists, and faculty administrators). In the first round, only 58% of participating experts had worked at their institutions for more than five years, compared to 80% in the second round.

Table 3 demonstrates that 16 out of 25 items fulfilled the criteria for achieving consensus. Under the PPI activities in the faculty category, all items reached consensus. Three out of six items under the measures taken by the faculty to ensure the safety category reached a consensus (explaining and acquiring consent, taking precautionary measures, ensuring good medical care, and providing adequate monitoring and supervision). Meanwhile, two of the six items in the pressing issues in the PPI category reached consensus (confidentiality and privacy, and patients' understanding of their role). Two out of three reasons in the motivation for involvement category achieved consensus (monetary benefit, spirit of volunteerism). All three reasons for the importance of PPI achieved consensus. Finally, two of the three PPI issues during the COVID-19 pandemic reached consensus (limited availability, safety concerns).

Nine of the 25 items did not meet the consensus criteria. Three items were in the measures taken by faculty to ensure the safety category (keeping patient confidentiality and privacy, ensuring patient safety, and ensuring student and staff safety), and four items relating to the pressing issues in the PPI category (safety and care for the patient, honorarium payment, acknowledgement of the patient's role, and awareness of patients' group having access to information on teaching and learning).

One item was in the motivation for involvement category (medical care benefit), and another in the issues with PPI during the COVID-19 pandemic category (PPI alternatives).

Table 2: Demographics of the educators

Participants' background	First round, N (%)	Second round, N (%)
Number of experts	19	40
Medical schools		
Public	14 (73.7)	38 (95.0)
Private	5 (26.3)	2 (5.0)
Faculty role		
Clinical educators	4 (21.1)	24 (60.0)
Medical educationists	4 (21.1)	6 (15.0)
Administrators	3 (15.8)	7 (17.5)
Others	8 (42.0)	3 (7.5)
Working experience		
≤ 5 years	8 (42.1)	8 (20.0)
6–10 years	4 (21.1)	6 (15.0)
11–15 years	3 (15.7)	17 (42.5)
≥ 15 years	4 (21.1)	9 (22.5)

Table 3: Round two of the Delphi study

Constructs/items	Triangular Fuzzy numbers		Fuzzy evaluation			
	Threshold value (d)	Percentage of consensus (%)	m1	m2	m3	Fuzzy score (A)
PPI activities at the faculty						
Teaching and learning	0.082	97.5	0.545	0.745	0.945	0.745
Assessment	0.122	92.5	0.510	0.705	0.905	0.707
Student research	0.124	80.0	0.410	0.610	0.810	0.610
Engagement with patients	0.120	90.0	0.500	0.700	0.900	0.700
Measures taken by the faculty to ensure safety						
Explaining and acquiring consent	0.111	92.5	0.515	0.715	0.915	0.715
Keeping patient's confidentiality and privacy	0.187	47.5*	0.120	0.250	0.450	0.273*
Taking precautionary measures and ensuring good medical care	0.104	95.0	0.520	0.720	0.920	0.720
Providing adequate monitoring and supervision	0.113	92.5	0.510	0.710	0.910	0.710
Ensuring patient safety	0.129	80.0	0.045	0.135	0.335	0.172*
Ensuring student and staff safety	0.103	85.0	0.030	0.150	0.350	0.177*
Pressing issues in PPI						
Confidentiality and privacy	0.159	75.0	0.410	0.600	0.800	0.603
Safety and care for the patient	0.192	42.5*	0.395	0.580	0.780	0.585
Honorarium payment	0.176	60.0*	0.340	0.535	0.735	0.537
Acknowledgement of the patient's roles	0.176	55.0*	0.360	0.550	0.750	0.553
Patient's understanding of their roles	0.154	80.0	0.415	0.605	0.805	0.608
Patient groups have access to information on teaching and learning	0.187	47.5*	0.120	0.250	0.450	0.273*
Motivation for involvement						
Monetary benefit	0.146	80.0	0.320	0.510	0.710	0.513
Medical care benefit	0.167	72.5*	0.300	0.485	0.685	0.490*
Spirit of volunteerism	0.096	87.5	0.425	0.625	0.825	0.625
Importance of PPI						
Patients and the public are important stakeholders	0.097	97.5	0.525	0.725	0.925	0.725
Application of knowledge	0.088	100.0	0.535	0.735	0.935	0.735
Authentic learning resources	0.119	92.5	0.515	0.715	0.915	0.715
Issues with PPI during the pandemic						
Limited availability	0.107	82.5	0.410	0.605	0.805	0.607
Safety concerns	0.101	87.5	0.420	0.615	0.815	0.617
PPI alternatives	0.169	67.5*	0.295	0.490	0.690	0.492*

Note: * Not meeting the criteria for achieving consensus

DISCUSSION

This study assessed the importance of PPI in Malaysian medical education to propose a culturally responsive PPI framework. These aims were driven by medical educators' consensus on all items under the PPI activities related to teaching, learning, and student assessments across different regions (22, 23) and justified by the high involvement of patients and the public revealed in the current study. As existing theoretical concepts are arbitrarily defined using global, predominantly Western conceptualisations of medical education, it is essential to refine the PPI framework based on local or regional knowledge, given the interplay of context and complexity (22). Matthews et al. (24) noted that most strategic documents lack depth and clarity in critical domains, despite institutional commitment to PPI. Therefore, it is crucial to emphasise socioculturally responsive conceptualisations, particularly to enhance the engagement and empowerment of PPI locally, as well as to address the power of co-creation at a more granular level (25). Information sharing, leveraging community participation, and decentralising healthcare will ensure equitable PPI participation at all levels of healthcare and medical education. Moderate decentralisation has been shown to lower public expenditure and extend life expectancy, as patients actively participate in maintaining their own health (26).

In the present study, the importance of PPI in medical education was determined based on the medical educators' consensus on the perception that patients and the public are essential stakeholders who receive medical care. They are authentic learning resources in which clinical knowledge is applied. Medical educators recognised that PPI was critical even during the COVID-19 pandemic. Despite raising safety concerns, they agreed that PPI should continue with adequate screening and restriction. Given the complexity of PPI in medical education, a whole system approach is essential—one that critically examines the context of patient involvement, identifies enablers and barriers, and addresses the influence of unequal power dynamics (27). Beyond patient safety risks, medical educators dismissed the idea that an alternative to PPI is more appropriate, indicating that PPI is vital regardless of the circumstances. The medical educators also rated the spirit of volunteerism highly as a reason for PPI. This finding aligned with earlier studies in which patients willingly participated in medical education conducted by health care providers and refused payment (28, 29). Their volunteerism extended to various tasks, such as sharing ideas and commenting on new teaching initiatives, recommending innovations, evaluating students' level of patient-centeredness based on their feedback, and discussing significant events. In the past, an individual's commitment to PPI has been linked to a sense of entitlement to special treatment (29), but the medical educators' opinions on whether PPI is motivated by medical care benefits were relatively divided in this study.

PPI is conventionally conceptualised as a spectrum of involvement. At the lowest level, the patient is only the focus of the clinical scenario (without direct involvement), while at the highest level, the patient is involved at the institutional level and policy-making bodies (18). In the current study, the experts were not evaluated on their understanding of the context of active involvement. Their ratings were based solely on their background knowledge of PPI in medical education at their institution. Furthermore, the medical educators' consideration of active participation in this study was limited to the scope of teaching, learning, assessment, and research. This perspective contradicted the literature, which reported that patients' involvement ranged from passive to active participation and from self-focused to teaching-focused (30). In countries such as Singapore, where cultural norms favour patient passivity, PPI is advocated as a lens through which to view collectivism, in which the sum of all parts

is valued above and beyond individual participation (31). The representativeness of PPI is also reflected in other aspects of the healthcare system, such as the establishment of Health Technology Assessments and Clinical Practice Guidelines (32).

The emphasis of PPI in the Malaysian medical education settings remains lacking and has not received the proper support, including transparent communications towards community involvement. When a key process in medical education is labelled as ‘secondary’, resources cannot be invested to sustain the programme. The PPI will continue to be seen as peripheral or a ‘passive presence’ if medical educators refrain from championing this programme as a critical equal source of expertise on health and illness experience (33). The lack of consensus among Malaysian medical educators reflects their view that PPI has not significantly impacted patient outcomes, contrary to what is established in other countries (e.g., the UK 4Pi National Involvement Standards). This finding underscores a major gap and underscores the need for greater effort to ensure PPI in medical education is acknowledged and addressed appropriately, with a balanced framework that considers the complexity of the issues at hand. Baines and Regan de Bere (3) outlined 13 principles that can help optimise PPI. Perhaps the most interesting findings from their study were the division of essentials: when consensus was reached, and desirable principles: when consensus was not reached, which exemplifies a positive connotation to elements that did not achieve consensus as being present, even when not prioritised.

The medical educators in this study were less concerned about the medical faculty recognising the roles of PPI in medical education. This ambiguity is reflected in their lack of consensus on the patient’s awareness and the public’s access to information on teaching and learning. The experts assumed that the roles of PPI were within the scope and were implemented appropriately in their medical schools. This finding is in tandem with the study by Gray-Burrows et al. (34), which highlighted that PPI implementation was conducted to “just-to-tick-boxes and please funders”. At present, the patients and the public are expected to understand their roles without proper education or training, potentially leading to poor efficacy of the PPI in medical education (35). The power hierarchy, for example, unintendedly marginalises patients and public involvement in medical education as they are often treated as passive learning tools due to their illness (10). Therefore, it is recommended that patients and the public be provided with ample educational information before participating in PPI activities. Baines and Regan de Bere (3) emphasised that acknowledging, rewarding, and valuing individuals involved is one of the vital PPI principles. The PPI should be a voice-giver instead of a silencer, and their involvement must be measured beyond logistical efficacy, including how respectfully the relationship is conducted (35).

Debates concerning mechanisms of empowering patients beyond tokenism continue to occur (36). The lack of consensus among medical educators about PPI honorarium payments also follows the same theme. Most medical educators recognised the importance of providing reasonable compensation to patients and the public who agreed to participate in medical education. They assumed that the payment given to participants by the medical faculty was sufficient; thus, the issue was not a major concern. The medical educators also agreed that patients’ and the public’s participation in PPI programmes was likely motivated by monetary benefits. Thus, institutions are recommended to raise awareness of this issue, provide better remuneration through greater access to PPI initiatives, and prevent exclusivity in participation (36). The exclusivity can range from barriers to equality and discriminatory practices based on social classes or disability, geographical distance, and patients’ living conditions. These biases are particularly true in cases of homelessness and marginalised persons in prisons, patients, and individuals with communication issues

or ‘difficult patients,’ such as the deaf or blind, non-natives, and those who are not well-versed in the primary language. Poor health literacy and healthcare accessibility are also major constraints that prevent minority groups from participating in PPI programmes (37). Therefore, medical educators should strive to make PPI more inclusive for patients and the public (38).

The medical educators were aware of the safety concerns of PPI in medical education. They agreed that appropriate measures were taken at their respective medical schools to ensure participants’ safety. The consensus achieved on most measures to ensure PPI safety parallels their least concern about patient safety and care. The issue of patient safety could be related to time pressure (39), such as during high-stakes examinations. Patients, particularly those who are newly involved in PPI, were also anxious and concerned about their safety, privacy, and confidentiality (2). Nonetheless, the institution’s lack of emphasis on this aspect reflected the lack of consensus on maintaining PPI’s privacy and confidentiality, highlighting the pressing need for a clear PPI framework in medical education and an ethical anchor to ensure patient and public safety. An earlier study emphasised that the widespread recognition of the value of PPI is instrumental in sustaining involvement and the positive impact of participation (40). Therefore, all medical institutions should prioritise safety, privacy, and confidentiality to ensure retention and sustainability of patients’ involvement.

In the present study, medical educators disagreed that patient, student, and staff safety were being jeopardised during PPI in the medical programme. Earlier studies have reported invisible ethical challenges, such as emotional burden, may expose students to the patients’ traumatic history, leading to students requiring emotional support to deal with the PPI experiences (35). Additionally, the patients reported the intrusive nature of the students’ inquiries concerning their illness (30), which can be described as retraumatisation (35). The low awareness and limited emphasis on appropriate training, due to the absence of a transferable PPI framework, may have unintended consequences (11). Training efforts could also be constrained by limited empirical evidence on the benefits of PPI for medical education (41). Considering the lack of reflexivity in existing frameworks, the future Malaysian PPI framework in medical education must be anchored in “care ethics, emotional safety, epistemic justice and relational accountability” (35).

Implications of PPI to Medical Training in Malaysia

The implications of PPI for medical education in Malaysia are multifaceted and significant. Integrating PPI into medical training potentially improves curriculum development through patient-centred learning and formal feedback mechanisms. In addition, a clear PPI framework can enhance students’ communication skills and foster empathy, which are crucial for establishing effective doctor-patient relationships (32). The diversity in patients’ perspectives will also help students understand the cultural contexts and health beliefs that underpin a multicultural society such as Malaysia, while encouraging culturally competent care.

In the same vein, the current study highlighted the advantages of empowering patients by including patients’ perspectives and active participation that must be explicitly emphasised in the healthcare system (32). Their involvement may be fiscally motivated, and acknowledging this possibility will allow institutions to reflect more broadly on the equitable financial implications of PPI in student learning and assessments. Inadvertently, PPI also increases access to healthcare and indirectly shapes the quality of medical doctors.

Limitation

Despite significant findings regarding consensus on most items, this study has several limitations. Firstly, the absence of participants' continuity in the Delphi responses might affect the significance of the study's outcomes. Poor responses from participants in round one to continue participating in the second round prompted the researchers to recruit a different cohort of educators from multiple medical schools. Nevertheless, this change is acceptable because the Delphi principles mainly emphasise the use of experts in the field, and this core principle was observed throughout the study. Secondly, the iteration was halted after the second round due to poor response rates from more than 100 invitations. Only 40 educators responded; thus, the researchers proceeded with data analysis using the existing data to preserve the validity of the results. Based on the findings, the number of consensus achieved in round two was acceptable as the final consensus from the experts.

CONCLUSION

This study is the first to explore educators' perspectives on PPI in Malaysian medical education, grounded in the critical aspects identified in the literature. The consensus indicated that educators from various medical schools in Malaysia shared similar perspectives. These findings suggested the importance of developing standard protocols for PPI. The educators' consensus will be compared with that of the students, patients, and the public in future exploratory studies.

ACKNOWLEDGEMENTS

This study is a part of the research funded by the Fundamental Research Grant Scheme, Kementerian Pendidikan Tinggi Malaysia, grant code FRGS/1/2019/SS06/USIM/02/2.

ETHICAL APPROVAL

This study was approved by the Universiti Sains Islam Malaysia Human Ethical Committee (ETHICS COMMITTEE/IRB REF NO: USIM/JKEP/2020-83).

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