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# Medical student attitudes to patient involvement in healthcare decision-making and research

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# Medical student attitudes to patient involvement in healthcare decision-making and research

## Objective

Patient involvement is used to describe the inclusion of patients as active participants in healthcare decision-making and research. This study aimed to investigate incoming Year 1 medical (MBChB) students' attitudes and opinions regarding patient involvement in this context.

## Methods

We established a staff-student partnership to formulate the design of an online research survey, which included Likert scale questions and three short vignette scenarios designed to probe student attitudes towards patient involvement linked to existing legal precedent. Incoming Year 1 medical students (n = 333) were invited to participate in the survey before formal teaching commenced.

## Results

Survey data (49 participants) indicate that students were broadly familiar with, and supportive of, patient involvement in medical treatment. There was least support for patient involvement in conducting (22.4%), contributing to (34.7%) or communicating research (30.6%), whereas there was unanimous support for patients choosing treatment from a selection of options (100%).

## Conclusion

Incoming members of the medical profession demonstrate awareness of the need to actively involve patients in healthcare decision-making but are unfamiliar with the utility and value of such involvement in research. Further empirical studies are required to examine attitudes to patient involvement in healthcare.

**Keywords:** patient involvement; decision-making; healthcare; medical research

# Medical student attitudes to patient involvement in healthcare decision-making and research

## Introduction

Patient and public involvement (PPI) describes active collaboration between patients and/or the wider 'public' and researchers. In its broadest sense, PPI gives growing recognition of the need for *inclusive* models of healthcare which view patients as active participants in, rather than passive recipients of, healthcare decision-making and research [1][2].

The historical roots of PPI in healthcare can be traced back to the civil rights movement of the mid-1950s which challenged authoritarianism in favour of democracy [3]. In seeking such democratic input to healthcare, patient support and advocacy groups were formed to challenge traditional forms of medical authoritarianism so that patient and public voices were heard. According to Wilson and colleagues, such was their moral rights as tax-paying 'consumers' of the National Health Service (NHS) [3]. In the early 2000s, a statutory 'Duty to Involve' patients in policymaking was introduced in England [4] whilst the Health and Social Care Act 2008 required researchers to demonstrate PPI in their work [5][6]. PPI in research may help influence priority setting, experimental design, and future research applications, all of which can improve overall research design [7][8][9]. PPI promotes the patient as an 'expert in experience' with their own, unique epistemic value that can enhance research [10]. Patients and the public may be involved in the conduct of, contribution to, and communication of, research. Accordingly, greater patient involvement in healthcare research has been shown to improve health outcomes, mitigate against patient harm and improve patient experiences [11][12].

However, in terms of patient involvement in healthcare decision-making, the move away from beneficent authoritarianism progressed at a far slower pace [13]. The culmination of case law examining the parameters of adequately informed consent came in the Supreme Court ruling of *Montgomery v Lanarkshire Health Board* [2015] which ultimately mandated greater patient involvement in decisions about their own care. In her ruling, Lady Hale clarified that patients are no longer to be viewed as "...passive recipients of the care of the medical profession..." [14 at s.75]. As a result, there have been noticeable recent moves to adopt models of 'shared' and 'supported' healthcare decision making [15][16].

To contribute to the existing scholarship on PPI in healthcare decision-making and research, we sought to develop greater appreciation of the pre-conceived attitudes held by incoming members of the medical profession (Year 1 medical students). Our aim was to determine what pre-conceived attitudes these students held towards patient involvement in healthcare.

## Methods

### Design

To ensure effective communication with the study target group (Year 1 medical students), we established a staff-student partnership with four Year 2 medical students from the design phase of the study. The student partners (co-authors BDS, AN, YR, LY) had each recently completed a Student Selected Component (SSC) project on '*Patient Perspectives in Research*' supervised by author KM. SSCs are short modules, chosen by students, which allow them to study an area of interest in more depth – a requirement of the General Medical Council (GMC) [17 at s.94]. In completing their SSC, the student partners each conducted a literature review and designed their own PPI project. We adopted a staff-student partnership model reflective of the '*student as apprentice*' dynamic described in Olsen's 'Student Partnership Framework' to facilitate the shared pursuit of knowledge and to support development of our student partners' research skills [18][19].

All authors met on 9<sup>th</sup> February 2022 to discuss the scope of the project and to outline expected commitments. To establish the study aims and research design, all authors met again on 21<sup>st</sup> February 2022. During this meeting, staff partners (JO and KM) discussed the background to the study, proposed study aims, and offered potential research questions for student partners to evaluate. The student partners were given time to discuss the proposed project amongst themselves and were provided whiteboard pens, post-it notes and paper to record their thoughts and amendments.

At the end of these discussions, authors agreed to conduct an exploratory research survey with the research aim of examining incoming medical students' attitudes to patient involvement in healthcare decision-making and research. Student partners were interested in exploring student perceptions at all levels of academic study, however pragmatic constraints (e.g. academic research time), led us to focus on incoming medical students for this initial study. A further outcome of this meeting was the suggestion to contextualise some statements in the research survey (for example "*doctors should work in partnership with patients*") with a scenario. Subsequently, JO developed three scenarios to directly reflect current legal precedent and relevant regulatory issues pertaining to patient involvement in healthcare (Table 1).

Table 1. Three ethical scenarios were drafted in collaboration with student partners and were designed to interrogate the students' views related to existing legal precedent ('rationale'). The scenarios and corresponding options are provided in the table, as they appeared in the survey, alongside participants' responses (n = 47).

Scenario	Rationale	Scenario and survey response options	Response [No. (% total)]
1	Representative of the case of <i>Montgomery v Lanarkshire</i> [2014] - which holds that patients must be informed of the benefits, material risks and reasonable treatment alternatives [at 87; 90] – scenario 1	An expectant mother known to have type 1 diabetes mellitus is admitted to the labour ward and is expected to give birth soon. The mother, who is also of short stature, asks doctors whether there are any risks that she	

	describes the case of an expectant mother with type 1 diabetes mellitus due to deliver a larger than average baby. Participants were asked whether doctors should inform the mother of risks and alternative treatment options.	should be made aware of. Doctors know that since the mother has diabetes mellitus, she is more likely to be carrying a larger than average baby and that there may be several known complications associated with giving birth naturally compared to via a caesarean section. What should the doctors do?	
		Do not tell the patient of the risks and make a decision on her behalf	0 (0.0)
		Tell the patient of the risks and any options available	47 (100.0)
2	Representative of the well-established Torts of Negligence and Battery as they relate to medical consent (see, for example, <i>Schoendorff v Society of New York Hospital</i> 1914; <i>Bolam v Friern Hospital Management Committee</i> , 1957). Participants were asked whether a surgeon undertaking surgery on a patient for a specified purpose could then undertake an additional, non-urgent procedure without explicit consent.	A patient consents to undergo minor surgery to have a mole removed. During the surgical procedure, however, doctors discover that the patient requires an additional (non-urgent) surgical intervention. This was not previously discussed with the patient. What should the doctors do?	
		Proceed with the additional surgical intervention	3 (6.4)
		Waken the patient and ask for their consent before continuing	44 (93.6)
3	Representative of the recommendations made in <i>First Do No Harm</i> relating to increased patient input to innovative medicines and medical devices development (Cumberlege, 2020, see ss.2.135, 2.81, 2.107). Participants were asked whether researchers should take patients' lived experience into account or rely solely upon scientific clinical trial evidence during evaluation.	A group of doctors are involved in pioneering a new surgical technique using a new implant. Some months after the initial surgical implantations were performed, patients begin to complain of painful side effects. This is in spite of the fact that clinical trial data is strongly in favour of this new technique and shows little, to no, side-effects. What should the doctors do with this information from their patients?	
		Disregard this information and continue to rely upon the scientific	0 (0.0)

		clinical trial evidence to provide the implantation for new patients	
		Explore the existing patients' experiences in more depth and use this to shape future practice	47 (100.0)

Our study took place before the Supreme Court ruling in *McCulloch v Forth Valley Health Board* [2023] which clarified that determination of 'reasonable treatment alternatives' is a matter of professional judgment which does not need to include the patient [20]. Accordingly, the earlier ruling in *Montgomery* which held that patients be informed of the benefits, material risks and reasonable treatment options was used in our scenarios [14]. Following the initial draft, KM and student partners advised on and edited the wording of the scenarios. An iterative feedback loop was established thereafter, whereby all authors discussed and edited the research survey until a consensus was reached.

### Ethical approval

Approval for this study was obtained from the College of Medical, Veterinary and Life Sciences Ethics Committee for Non-clinical Research Involving Human Participants [No: 200210131] with staff and student partners included as named researchers. The ensuing collection, storage and processing of personal data was in accordance with the Data Protection Act 2018 [21].

### Recruitment

The survey (Supplementary File 1) was built and disseminated via Qualtrics (Qualtrics LLC 2022) using an institutional license. Incoming Year 1 medical students (n = 333) were invited to participate in the research study on 2<sup>nd</sup> September 2022 via an announcement posted on the institutional virtual learning environment, Moodle. An additional reminder was posted on 21<sup>st</sup> September 2022. The release of the survey in this manner, prior to the start of the academic year (20<sup>th</sup> September 2022), was made possible on account of our well-established mandatory online pre-entry induction course which all Year 1 medical students gain access to before formal teaching begins [22][23]. A pragmatic decision was taken to close the survey on 22<sup>nd</sup> September 2022 before students' first scheduled lecture on the topic of ethics to remove the potential for influence of this teaching on the study results. In this small-scale study, our aim was to gather an insight into the attitudes of new members of the medical profession at our institution, rather than to generalise to a broad population.

### Results

Responses were disregarded from analyses where only demographic information was given (n = 6). Subsequently, three partially complete and 46 complete responses were included in the analyses (49 total, 14.7% of year group). Most participants were female (40/49, 81.6%), between 18-21 years old (36/49, 73.5%) and had joined the University directly from school (36/49, 73.5%). Demographic characteristics of participants are summarised in Table 2.

Table 2. Demographic characteristics of survey participants.

<b>Characteristic</b>	<b>No. (% total)</b>
<b>Gender</b>	
Female	40 (81.6)
Male	9 (18.4)
Not listed	0 (0.0)
Prefer not to say	0 (0.0)
<b>Age</b>	
17 or under	9 (18.4)
18-21	36 (73.5)
22-25	3 (6.1)
26-29	1 (2.0)
30+	0 (0.0)
Prefer not to say	0 (0.0)
<b>Educational background</b>	
Foundation course or pre-med	3 (6.1)
Gap year	4 (8.2)
Graduate	4 (8.2)
Repeating or returning to Year 1	2 (4.1)
School leaver	36 (73.5)
Other	0 (0.0)

Survey participants were asked to rate how much they agreed or disagreed with seven statements on a five-point Likert scale (Figure 1). Most students (35/49, 71.4%) agreed or strongly agreed that patients' lived experience should be valued as much as clinical knowledge or expertise. All participants agreed that it is important to represent the patient voice in healthcare (4/49, 8.2% agreed; 45/49, 91.8% strongly agreed), to consider patient input alongside scientific findings (23/49, 46.9% agreed; 26/49, 53.1% strongly agreed) and to involve patients in management decisions (9/49, 18.4% agreed; 40/49, 81.6% strongly agreed). Conversely, four participants (8.2%) agreed that a doctor should have the final say in decision-making and some participants said that patients should be the passive recipients of care (3/49, 6.1% agreed; 1/49, 2.0% strongly agreed).



Participants were presented with three scenarios related to an existing legal precedent of which the participants were not informed and were asked to choose what the doctors should do in each scenario. All participants (n = 47) chose the option that aligned with the legal precedent for scenarios 1 and 3 (Table 1). In scenario 2, participants were asked whether a surgeon undertaking surgery on a patient for a specified purpose could then undertake an additional, non-urgent procedure without explicit consent. Three participants (6.4%) opted to proceed with the additional surgical intervention in this scenario (Table 1).

Participants were asked to select aspects of healthcare that they thought patients could be involved in from a standard list (Table 3).

Table 3. Ways for patients to be involved in healthcare. Survey participants (n = 46) could select multiple options.

<b>Which aspects of healthcare do you think patients can be involved in?</b>	<b>No. of responses (% total)</b>
<b>Choosing treatment from a selection of options</b>	46 (100)
<b>Communicating research findings</b>	15 (32.6)
<b>Conducting research</b>	11 (23.9)
<b>Contributing to the design of research studies</b>	17 (37.0)
<b>Deciding where to receive healthcare</b>	41 (89.1)
<b>Medical decision-making about treatment</b>	30 (65.2)
<b>None of the above</b>	0 (0.0)

They could select multiple options. The most popular options were 'choosing treatment from a selection of options' (46/46, 100% of participants) and 'deciding where to receive healthcare' (41/46, 89.1%). Fewer participants selected options related to designing (17/46, 37.0%), conducting (11/46, 23.9%) or communicating medical research findings (15/46, 32.6%).

To explore participants' own experiences, participants were asked whether they felt their opinion had been valued in their own experience of healthcare. Closed text responses (Table 4) indicated that most participants felt that their opinion had been valued (29/38, 63.0%).

Table 4. Participants were asked to disclose whether they felt their opinion has been valued in their own experience of healthcare (n = 46).

<b>In your personal experience with healthcare, have you felt that your opinion has been valued?</b>	<b>No. female (% female)</b>	<b>No. male (% male)</b>	<b>No. overall respondents (% total)</b>
<b>Yes</b>	23 (60.5)	6 (75.0)	29 (63.0)
<b>No</b>	9 (23.7)	0 (0.0)	9 (19.6)
<b>Not applicable</b>	6 (15.8)	2 (25.0)	8 (17.4)

Nine participants (19.6%), all female, felt that their opinion had not been valued.

## Discussion

To the best of our knowledge, this is the first study in the UK to examine medical student attitudes towards patient involvement in healthcare decision-making and research. Our findings demonstrate that participants were broadly supportive of patient involvement in key aspects of medical decision-making yet less supportive of research involvement.

### Patient Involvement in Research

The NIHR defines patient involvement in research as “*research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them*” [24]. This reflects a model of shared decision-making whereby the epistemic value of the patient is recognised at the research and development stage of product development [2]. Our data indicate less support, in a new medical student cohort, regarding general patient involvement in research compared to healthcare decision-making. Students were less aware of opportunities to involve patients in conducting, contributing to, and communicating research. Our findings are reflective of a systematic review by Biddle et al., (2020) which found growing support for the concept of patient involvement in healthcare but “*to a lesser extent, in health research*” [25 at p24]. Biddle and colleagues describe the UK as a leading contributor to patient involvement in research compared to several other European countries [25]. They note that, whilst the “*general attitude towards ... [patient involvement...] is changing*” to reflect more acceptance, it is often in a “*marginal or tokenistic*” sense [25 at p24]. Similarly, a study by Boaz et al., (2016) suggests that researchers demonstrate “*active resistance*” [26 at p600] to sharing control of the research process with patients constrained to “*tinker[ing] at the edges*” [26 at p592]. Such attitudes appear to be reflected in our incoming medical student cohort, the majority of which did not agree that patients can be involved in research processes (Table 3). It is vital to address why attitudes towards patient involvement in the research process is less agreeable. These combined findings indicate that there may be a need to improve student awareness of the role, and benefits, of patient involvement in research.

### Patient Involvement in Healthcare Decision-Making

In healthcare, shared decision-making is a complex process in which doctors diagnose the patient and then select appropriate treatment options for presentation to the patient. The initial selection of treatment is viewed as a matter of professional judgement which does not involve the patient [13][20]. Over a third of research participants did not indicate support for patient involvement in ‘medical decision-making about treatment’ (Table 3). For the purposes of informed consent according to *Montgomery*, patients should be informed of the reasonable treatment options [14]. Our participants demonstrated strong support for such patient choice from a range of treatment options. The General Medical Council (GMC) recognise that “*[d]ecision making is an ongoing process focused on meaningful dialogue*” [15 at p7]. Accordingly, once a treatment plan has been decided upon, the patient should continue to be informed as the condition is managed. There was unanimous agreement amongst our participants that doctors *should* involve patients in such treatment ‘management decisions’ (Figure 1). Further support for this premise may be derived from our participants’ strong support for the patient voice in healthcare which demonstrates respect for *inclusivity* and active participation in healthcare decision-making.

Overall, our incoming medical students demonstrated supportive attitudes towards patient involvement in informed, medical decision-making with most *against* doctors having the final say in decision-making and of patients being viewed as passive recipients of care. Such pre-conceived attitudes may derive from a clear sense of patients as consumers, and the growing role of consumerism in healthcare [27]. Responses to the scenarios (Table 1), which reflected key legal principles, may offer supportive evidence of this premise. Participants held unanimously supportive attitudes towards basic principles of consent, as per *Montgomery v Lanarkshire Health Board* [2015][14]. A small proportion of participants, however, demonstrated support for the performance of surgical procedures beyond the scope of initial consent, which fails to adequately involve and inform the patient. It is, therefore, important that incoming members of the profession are made aware of the dynamic and *ongoing* nature of consent during medical training, such as through vocational skills or clinical placement teaching.

### Strengths and Limitations

We acknowledge that social desirability bias (SDB) – defined by Zerbe and Paulhus (1987) as “*the tendency of individuals to present themselves favourably with respect to current social norms and standards*” – may have led our participants to respond in a manner ‘expected of them’ [28 at p250]. However, we recognise that as incoming medical students, our participants would have been expected to demonstrate basic awareness of pertinent medical issues in their medical applications and interviews and are therefore likely to have had pre-existing knowledge that influenced their attitudes to PPI in a positive manner. Additionally, high non-response rates in voluntary surveys are well-documented. Indeed, Porter and Whitcomb (2005) suggest that the decision *not* to participate in a survey is multi-factorial; developing an appreciation of these factors may assist in interpreting the *quality* of data and could be explored in future work [29].

A key strength of our study lies in the involvement of medical students as active partners in our research team, which ensured appropriate communication with our target participants. *Strength* also derives from our inclusion of questions on demographics which enable us to draw hypotheses on the specific factors associated with response decisions. Most participants were ‘school leavers’ under the age of 21, which is broadly reflective of the cohort demographic [30]. The notably higher response rate from female medical students is not surprising given that the GMC reported that most medical entrants were women in 2022 [30]. Female medics are also more likely to spend time engaging in meaningful discussions with patients [31][32]. Such gender disparity may be linked to female egalitarianism or, indeed, the lived experiences of female medics as patients themselves, given the significantly negative correlations between female gender and integration into shared decision-making [33][34]. Indeed, fewer of our female participants felt that *their* opinion was valued in their personal healthcare experiences compared to males. Whilst we may conclude that interest in patient involvement positively correlates with survey engagement, we may *conversely* assume that some non-participants may have found the subject matter to be ‘*boring*’ or to lack relevance which may have utility for medical curriculum development to ensure students are engaged on the subject [29 at p129].

### Future Research

There is scope for future qualitative research to examine *why* some participants are less inclined to involve patients in research design and dissemination of results. Furthermore, the evolution of student attitudes towards PPI is something that we are keen to explore further. There is evidence to suggest that medical student attitudes can be shaped by their experiences in the clinical environment and from

exposure to the negative attitudes of practicing clinicians [35]. Such research may align with existing work which suggest that empathy – *“one of the most highly desirable professional traits”* and *“crucial for [establishing the] successful physician-patient”* relationship that underpins meaningful patient involvement – erodes over time [36 at p244].

## Conclusion

Incoming medical students demonstrate awareness of the need for patient involvement in healthcare treatment but lack appreciation for the role of patient involvement in medical research, despite the long-established history of PPI in research. Further empirical studies are required to determine whether such favourable attitudes to patient involvement wane over time. We anticipate that our collective findings may serve as the basis for future research and may have utility for promoting ongoing medical education to promote the value of patient involvement in medicine and health research.

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## Figure Legend(s)

Figure 1. Participants' responses to Likert scale statements (n = 49).