

# ENHANCING PATIENT ACCESS TO MEDICAL RECORDS IN MALAYSIA: A DECENTRALISED REGULATORY APPROACH

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## ABSTRACT

*In Malaysia, patient access to medical records faces significant obstacles despite formal recognition of this right by the Malaysian Medical Council (MMC). This study scrutinises the centralised regulatory framework enforced by the MMC and the Ministry of Health (MoH), highlighting its failure to effectively translate recognised rights into actual practice within healthcare settings. This paper proposes a decentralised model to foster more effective, patient-centric care. By analysing gaps in regulatory enforcement that impede access to medical records, the study suggests strategic reforms to enhance stakeholder engagement and catalyse behavioral changes among healthcare providers. This approach aims to create a more adaptable and resilient healthcare framework, addressing both regulatory non-compliance and the pressing need for systemic reform.*

**Keywords:** Patient Access, Medical Records, Malaysia, Decentralised Regulation.

## INTRODUCTION

The Malaysian Medical Council (MMC) explicitly recognises the right of patients to access their medical records, a right that is crucial for enabling informed healthcare decisions. According to MMC guidelines, patients are entitled to view their personal health information and can request these records formally from healthcare providers, who are obligated to comply within a reasonable timeframe (Malaysia Medical Council, 2006). These guidelines are designed to ensure confidentiality and secure handling, allowing only authorised personnel to access medical records and stipulating reasonable fees for copies.

However, despite these clear guidelines, there is a notable discrepancy between the rights recognised by the MMC and their practical application within healthcare settings across Malaysia. This gap highlights significant issues in regulatory enforcement and compliance, suggesting a lack of effective translation of these rights into actionable practices. Many healthcare providers fail to adhere strictly to these guidelines, often necessitating court orders for patients to gain access to their records (Nurul et al., 2015).

This disconnect underscores the broader regulatory challenges faced by the healthcare system in Malaysia, as previously discussed. It emphasises the need for a more decentralised regulatory approach that not only enhances enforcement but also encourages greater stakeholder engagement and behavioural change among healthcare providers. By addressing these gaps, Malaysia can better align formal guidelines with actual practice, ensuring that patient rights are upheld effectively and consistently across all healthcare settings.

## Regulation and Its Challenges

Regulation remains a multifaceted and contested concept within both theoretical and practical domains. Significant scholarly attention has been given to formal state regulation,

which encompasses all the codified laws and regulations enacted through legislative processes or formal decrees (Thomson & Freudenberger, 1997). On the other hand, non-formal rules, often referred to as 'soft laws,' may be unwritten and are not legally binding or enforced. These include guidelines that, despite their informal status, play a crucial role in shaping practices within various sectors.

Proponents view regulation as 'technocratic device that has the potential to exert rational controls over important economic and social activities' (Baldwin et al., 2011). Regulation has been described in diverse ways; for example, Selznick defines it as 'sustained and focused control exercised by a public agency over activities that are valued by the community' (Selznick, 1985). Baldwin presents three main conceptions of regulation: first, as the issuance of an authoritative set of rules with mechanisms for ensuring compliance; second, as efforts by state agencies to guide the economy; and third, as encompassing all forms of social control, including unintentional and non-state processes (Baldwin et al., 2011). This broad understanding leads to the 'smart regulation' hypothesis, which posits that regulation can be effectively implemented by a variety of entities beyond state institutions, such as corporations, self-regulatory organisations, professional or trade associations, and non-profits (Gunningham & Sinclair, 2017).

The 'regulatory space' concept, proposed by (Hancher & Moran, 1989), however argues that regulation is best understood through an analytical framework that considers how national, political, and legal settings influence the configuration of regulatory space and the distribution of power within it. This space, often dominated by large hierarchical organisations, is shaped by legal traditions and a mix of social, economic, and cultural factors. The diverse nature of the regulatory process and its openness to various actors are influenced by bureaucratic norms and historical regulatory practices.

In the context of Malaysia, this analytical approach helps to map out the roles of both state and non-state actors in facilitating patient access to medical records. The regulatory challenges faced by these actors highlight the need for a nuanced understanding of how regulation functions within different social orders. The central question then becomes whether both state and non-state actors can effectively encourage and enhance moral and behavioral shifts towards more patient-centered care, or if a decentralised approach is necessary to better support and empower patients and healthcare providers in making informed choices that benefit patient care.

## **Decentred Regulation and its Role in Society**

The concept of 'decentralised regulation' offers a transformative lens through which the Malaysian regulatory landscape can be reassessed. This approach challenges the traditional centralised control of regulation, proposing instead that effective regulatory measures can arise from various, sometimes unexpected, sectors within society (Black, 2001). Such a framework is particularly pertinent in addressing the longstanding issues surrounding patient access to medical records in Malaysia.

Decentralised regulation encompasses a broad spectrum of ideas, asserting that 'governments don't have a monopoly on regulation and regulation happens within and between different social actors' (Black, 2002) and thus do not hold exclusive rights over regulatory processes. Instead, regulation occurs across different levels and sectors of society, involving a wide array of social actors. In the context of healthcare, this means that patients are not just passive recipients of care but are active participants in the regulatory aspects of clinical decision-making and policy development.

According to (Majone, 1997), regulatory agencies, which are often established by legislative statutes, play a pivotal role in this framework. These agencies are tasked with specific legal authorities and objectives, and their decision-making processes typically require public participation, thus allowing for a broader engagement in regulatory practices. In Malaysia, the Ministry of Health (MoH) and the Malaysian Medical Council (MMC) are primary examples of such bodies. Both are instrumental in overseeing health practices and upholding the standards of medical practice as dictated by the Medical Act 1971 and Medical Regulations 1974.

Despite the formal powers assigned to the MMC, its effectiveness is limited by its dependency on state funding and oversight by the MoH. This arrangement does not only stifle the MMC's autonomy but also its capacity to enforce regulations effectively. One significant area of concern is the restricted patient access to medical records, which is often only possible through court orders a clear indication of regulatory dysfunction and the failure of the MMC to enforce its guidelines. This failure highlights a critical issue in regulatory practices: when regulators cannot achieve the intended outcomes or effectively implement stipulated mandates, they are deemed ineffective. In Malaysia, the MMC's inability to ensure patient access to medical records without judicial intervention illustrates a profound regulatory shortfall. This situation is exacerbated by administrative and cultural practices that prioritise medical paternalism and limit patient autonomy, perpetuating a cycle of regulatory circumvention.

The concept of decentralised regulation suggests that moving away from a purely state-driven regulatory model towards a more inclusive approach involving various stakeholders could address these failures. This would allow for a more dynamic interaction between patients, healthcare providers, and regulators, potentially leading to more effective regulatory outcomes. In this model, the power dynamics within the healthcare system could be rebalanced, granting patients more significant roles and recognising their autonomy.

Adopting decentralised regulation in Malaysia could fundamentally change how patient rights, especially regarding access to medical records, are perceived and implemented. By recognising and empowering a broader range of actors within the regulatory framework, Malaysia can create a more responsive and effective health governance system. This shift would not only address the current deficiencies but also pave the way for a healthcare system that truly respects and upholds the rights and dignity of its patients.

## Overcoming Systemic Barriers

The Malaysian Medical Council's (MMC) inability to enforce patient access to medical records illustrates a systemic regulatory failure. The MMC, constrained by its reliance on governmental funding and oversight, lacks the autonomy to effectively mandate compliance, resulting in patients often needing court orders to access their medical records. This scenario underscores a fundamental issue: the unacknowledged rights and inconsistent regulatory authority are major obstacles in the path to reform.

Hierarchies within the healthcare system further complicate regulatory efforts (Grissinger, 2017). High-ranking professionals often resist changes proposed by regulatory bodies, undermining efforts to reform practices. This resistance is rooted in a complex interplay of legal, administrative, and medical logic that shapes the regulatory landscape, making it difficult to implement reforms effectively. The presence of deeply ingrained professional hierarchies means that meaningful regulatory change must address the power dynamics and knowledge asymmetries between different actors within the system.

The fragmented nature of regulation leads to significant disparities in how policies are understood and applied across different levels of the healthcare system (Black, 2001). This fragmentation often results in information asymmetry, where not all parties have access to the same knowledge or interpret it similarly. Such discrepancies can hinder effective regulation and contribute to the persistence of outdated practices that do not prioritise patient rights.

The regulation of patient access to medical records in Malaysia is a clear example of a complex space where no single actor has complete oversight or understanding. To address this, there is a need for a more integrated approach that involves multiple stakeholders, including patients, in the regulatory process. By doing so, the system can better reflect the diverse needs and rights of all parties involved. This approach aligns with the principle of decentralised regulation, suggesting that effective governance requires the active participation of a broader array of societal actors, not just those within traditional power structures.

Adopting a decentralised approach to regulation could lead to more effective governance in the healthcare sector by breaking down the barriers imposed by hierarchical structures and fragmented knowledge. By empowering patients and lower-tier healthcare providers, and by encouraging the involvement of a variety of stakeholders in the decision-making process, Malaysia can create a more equitable and effective regulatory environment. This shift would not only address the current deficiencies but would also ensure that the healthcare system is more responsive to the needs and rights of its patients.

The concept of complexity in regulation, as discussed by (Black, 2001), pertains to the dynamic interactions between various actors within a regulatory system and the social problems that arise from these interactions. In the Malaysian healthcare sector, this complexity is exemplified by the interactions between patients and doctors, which are significantly influenced by cultural, legal, and hierarchical dynamics. This complexity often results in regulatory practices that may not align with the intended outcomes, such as the reliance on court orders for accessing medical records, which exacerbates tensions and potential litigation (Antoci et al., 2016). The usual practice of obtaining medical records through court orders has not only placed a significant burden on patients but has also led to adverse emotional impacts on doctors involved in medical negligence disputes. This approach has solidified a culture of litigation rather than cooperation, which does not align with patient-centered care objectives. Effective reform in this area would involve dismantling the existing legal-centric approaches and promoting regulatory strategies that are inclusive of all stakeholders' views and are sensitive to the diverse cultural contexts of Malaysia.

To move towards a more decentralised regulatory framework, it is crucial for the MoH and MMC to foster strong collaborations that respect the autonomy and contributions of all healthcare participants. This could be facilitated by legislating new policies that encourage transparency and accountability, while also reflecting the diverse needs of the Malaysian population. Such legislation should not only focus on redefining access to medical records but also address the broader cultural dynamics that currently hinder effective healthcare delivery. Thus, adopting a decentralised approach to regulation in the Malaysian healthcare system requires a thorough understanding of the underlying social, cultural, and administrative barriers that currently impede effective governance. By acknowledging and addressing these complexities, Malaysia can develop a regulatory environment that truly supports patient empowerment and creates a healthcare system that is equitable, responsive, and culturally competent. This approach will ensure that regulatory practices are not just formally enacted but are practically effective, fostering a healthcare system that can adapt to the evolving needs and expectations of its diverse population.

## Legislation as a Catalyst for Behavioural Change in Patient Access

While decentralised regulation offers a broad framework for addressing the complexities and hierarchical challenges in the Malaysian healthcare system, legislation plays a crucial role in facilitating more immediate changes. Current practices, where hospitals and medical professionals withhold patient records unless compelled by court orders, highlight the need for legislative intervention to formalise patient rights. This legal backing is essential, not only to enforce compliance but to shift the underlying attitudes and cultural norms that currently hinder patient access.

As noted by Bliz and Nadler (Bilz & Nadler, 2014), laws are often effective because they carry the threat of punitive enforcement. This threat can be a powerful motivator for healthcare providers to alter their practices. The imposition of legal obligations under the assumption of justice serves as a legitimate mechanism to prompt behavioural change. However, as legislation reflects a compromise among diverse societal interests, achieving this change also depends on reaching a moral consensus within the community, particularly among those directly affected by the laws.

The effectiveness of legislation in changing behaviour extends beyond mere compliance; it also influences long-term attitudes. When combined with non-regulatory measures such as education and advocacy, legal mandates can foster a more cooperative relationship between healthcare providers and patients. This synergistic approach can help to normalise patient access to medical records, reducing the reliance on legal disputes to resolve access issues.

Despite the potential benefits of legislation, it is not a panacea. The existing legal framework in Malaysia already acknowledges the patient's right to access medical records to some extent. However, the challenge lies in enhancing compliance and shifting mindsets to broaden this access. Codifying common law principles into specific legislation could help compartmentalise and clarify these rights, making them more enforceable and understood across the healthcare landscape. To truly transform patient access to medical records, Malaysia must consider both legislative reforms and the adoption of a decentralised regulatory approach. This approach would involve various stakeholders in the regulatory process, including patients, who are often the most affected by regulatory failures. By empowering these stakeholders and ensuring their participation in the debate and formulation of new laws and guidelines, Malaysia can address the root causes of regulatory inefficiency and build a more responsive and inclusive healthcare system.

## CONCLUSION

Integrating legislative action with decentralised regulation provides a comprehensive strategy for overcoming the obstacles to patient access to medical records in Malaysia. This dual approach not only addresses immediate legal barriers but also tackles the broader cultural and systemic issues that sustain these barriers. By fostering a regulatory environment that is both legally sound and culturally sensitive, Malaysia can ensure that patient rights are upheld in a manner that respects the complexities of its diverse society.

The discourse on the decentralised regulation by Black, along with the examination of Malaysia's healthcare system, highlights significant regulatory failures exacerbated by a fragmentation of power, knowledge, and unrecognised autonomy. These issues manifest in a paternalistic doctor-patient relationship that has historically limited patient access to medical records, relying excessively on legal mandates such as court orders. Legislation, while crucial, cannot solely remedy the deep-seated issues within the Malaysian healthcare

regulatory framework. Its effectiveness hinges not just on the enforcement of rules but on the legitimacy and moral authority perceived by the public. The existing paternalistic practices, coupled with a general hesitancy among healthcare providers to fully embrace transparency, underscore a broader cultural and educational gap in patient-centered care.

For legislation to be truly transformative, it must go beyond imposing obligations and seek to cultivate a genuine dialogue among all stakeholders involved. It should address the underlying cultural norms and empower patients by making them active participants in their healthcare decisions. This approach would help shift the current paradigm from one where legal intervention is a necessity to one where it is a supportive measure within a broader, more cooperative healthcare system. Thus, the future of healthcare regulation in Malaysia should focus on creating a more equitable environment where the autonomy of patients is recognised and valued. This requires a comprehensive approach that includes legal reforms, enhanced education on patient rights, and a cultural shift towards more open and patient-focused healthcare practices. Only through such a multifaceted approach can Malaysia ensure that the changes are sustainable and that the healthcare system aligns more closely with the needs and rights of its patients.

In conclusion, while decentralised regulation offers a pathway to address the systemic issues within the healthcare sector, its success will ultimately depend on the collective efforts to redefine the roles of doctors, patients, and the legal system in a way that respects and upholds the autonomy and dignity of every individual seeking medical care.

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**Received:** 02-Oct-2024 Manuscript No. JLERI-24-15368; **Editor assigned:** 03-Oct-2024 Pre QC No. JLERI-24-15368(PQ); **Reviewed:** 17-Oct-2024 QC No. JLERI-24-15368; **Revised:** 22-Oct-2024 Manuscript No. JLERI-24-15368(R); **Published:** 29-Oct-2024