

# [Patient organizations in health care system in indonesia nursing essay](https://assignbuster.com/patient-organizations-in-health-care-system-in-indonesia-nursing-essay/)

The involvement of patients in health care system has been an interesting subject for recent decades. In the developed countries, the patients have sufficient room to take part in the health care system. On the contrary, in the developing countries, the patient is considered as the object of the system. As the consequences, patient interest is frequently underestimated and lead to violation of patient’s right. Many events such as malpractice of the physicians, medication error and untreated patients remains unreported. Herein, Patient organizations have the important role to represent the patient interest and to contribute more in health care system.

Indonesia, as the example of a developing countries in this paper, has admitted the right of patient through Act of Consumer Protection in 1999. However, the involvement of patient organizations in the system remains nothing. The current case of Prita Mulyasari has dramatically changed this paradigm. The role of patient organization in advocating Prita Mulyasari was a good example to express the power of public agency. Referring to Le Grand’s theory, patient organizations in Indonesia may be shifted from pawn towards queen, and should be taken into account as the actor in the health care system in Indonesia.

## Introduction

Generally, Indonesia adopts medico-technical models as the pattern of patient-care provider relationship (Nugroho 2005, Mulkan 2007, Antara 2007, Eki 2009). The model is determined by the medical experts where the care providers are considered as the best perfect agents that know with certainty of their decision regarding the health state of the patients (Folland, Goodman and Stano 2007). Instead of being equal, patient is situated subordinate to the medical care provider. This gap makes the patient as the passive party on this relationship model. They only follow what the doctor prescribed without any further objection to question what has the doctor done to them. This situation was described by Julian Le Grand (Le Grand 2003) as Pawn which reflects the individual who receives benefits as the passive victim of unavoidable circumstances. Apparently patients have less power to argue the decision of the provider even though it does not improve or even worsen their health state.

The winds of change on patient-provider relationship blown in 1999 after the enactment of The Act of Consumer Protection No. 08/1999, just a year after massive political reform. Afterwards, patients have more room to express their expectation and interest on the health care system, individually or collectively. However, this improvement was not so radical until the case of Prita Mulyasari occurred 10 years later after the act was enacted. Prita was an ordinary patient who experienced problem with health care provider that made her imprisoned for 3 months. She was released by the interventions from public and the advocation of patient organization, YLKI, as the main supporter on prita’s problem.

Prita’s story shows to us some facts regarding the position of patient in the system. First, individual patient does not have much power to question the decision of health care provider regarding her poor condition, therefore she chose to send public complaint after her legal complaint was being ignored by the hospital. Second, the involvement of patient organizations will result greater effect in advocating patient against lawsuit. This explains how importance the role of the patient organization as the representative of the patient in health care system. In line to Le Grand’s theory, in individual level patient might be a pawn which was a passive actor in the system. However, in the macro level especially when patient organization reflects the patient agency, it is actively become a queen which has power to determine their role in the system. These two different situations display the evolutionary role of patient in the health care system in Indonesia, and that is the main subject in this paper.

## Research Question

The central question of this paper is “ What has been the role and to extent the influence of patient organizations in the health care system in Indonesia ?”.

To answer the central question, this study constructs some sub-questions below :

Does the context of the country influence the role of patient organization ?

What was the role (and the position) of patient organization before prita’s case ?

Does prita’s case inspire “ a new wave” of patient-provider relationship ?

To answer these sub questions, this study will analyze some empirical findings regarding the question using Le Grand’s theory of motivation and public agency in the context of Indonesia health care system and the relationship between patient and health care provider.

## Study Objective

This paper provides determining factor which influences the role of patient organizations in the health care system in Indonesia. The key issue like indicated in the research question are the role and to extent of influence of patient organizations. This study will be useful particularly for policy maker to learn the behavior of patient organizations in Indonesia.

## Theoretical Background

## Government and Public involvement

In today’s political system, government is no longer considered as the single power which decides the goal of a state. Other parties are may have the equal power to govern policies for the sake of the state. Rose and Miller (Rose and Miller 2008) indicated that the principle of governmentality has risen in the new model of governance. According to Foucault (Foucault 1979), Governmentality means ensemble formed by the institutions, procedures, analyses, reflections, the calculations and tactics that allow to exercise of this very specific albeit complex form of power. He described that authorities have regulation to properly process the population, laws as instrument to adjust health, wealth, government capacity etc. However, society prefers another way of thinking that politically a priori to authorities tasks. They do not allow political power concentration on government but the notion of heterogeneity and diversity of groups in national territories for achieving various goal of the state, rather than giving the power to the government.

Governmentality implies smooth evolutional path of policies, for this reason, the idea of government underpins the diversity of powers and knowledge to deliver practicable and amenable intervention. Government does not simply different administrative agencies but a complex and heterogeneous condition that makes it possible for the object of policy to discuss, either agree or disagree to the administration.

In recognizing different capabilities of state involvement and societal actors that can be expected to have different motivation and capabilities for collective action, Helderman (Helderman 2007) distinguished four ideal typical governance arrangements : (1) the market and the principle of dispersed competition, (2) the community and spontaneous solidarity by mutual self coordination, (3) the state and hierarchical control or etatist governance, and (4) the associational order of private interest governments or corporatist governance.

Figure 1. The four ideal typical of governance arrangements (Reproduced from Helderman 2007)

In the ideal market and dispersed competition, profit maximization is the habitual action of economics entrepreneur and coordination between individual actors which is achieved through mechanism of market competition. This happens because the existing governance consists of large small number and categorical groups while the state is depicted as neutral actor, holding no substantive preference but reflects preference of powerful actors.

In the ideal community and mutual self coordination, collective identity is the common vakues where mutual commitment and equal solidarity is relatively easy to obtain and the individual actions easily be monitored by other members of the community. The homogeneity of the society tends to reduce the state function because the control is redistributed among the members although may always be option for state involvement.

In the ideal state and etatist governance, decisions are made by the state through the policy implementation. The state monopolies the legitimate compulsion and domination to protect the system from external factors and to manage the equitable and predictable treatment for all. Societal actors do not have power in this model since the state is the owner and provider of all services.

Last, in the ideal associational order and corporatist governance incorporates the self governing potential of societal actors combines with crucial variable of state capacities. Aggregation, mediation and negotiation among and between societal actors with public policy makers are the political space to create and implement policy. Both state and societal actors compromise to obtain agreement.

In the reality there is no model purely applied because most social policy regime configures the mixture of the state and societal actors in multiple institutional orders and multi layered governance arrangements. Different political, social and economic interaction in different circumstances are likely affect the modes of governance selected. In other words, however dominance a group whether it is state or societal actors, they might some mix of the four models.

## Motivation and Public agency in the system

In his theory about Motivation and Public Agency, Le grand (Le Grand 2003) explained motivation for an actor in the system in the terminology of Knight and Knaves. Knight represents an actor, for example health care provider that works based on purely altruistic preferences, while on the other hands, Knave reflects an actor that has pure self preferences in working. Le Grand displays public participation in chess game figures, Queen and Pawn. Queen refers to a party that actively involved in a system and represent independent actor that has the strong power to move, while pawn, on the other side, reflects agents that should walk step by step to achieve better position. Pawn receives benefits from the system as the passive victims of circumstances.

In the reality, human motivation and agency might be too complex to be adequately summarized by the terminology of knight, knave, queen and pawn because most of human being are in all probability some combinations of knight and knave and does not simply become either queen or pawn. Different aspects in different circumstances may affect the motivation and agency of individual. Though far too simplistic, Le Grand theory might be a clue for policy makers to design policies on the assumption that those affected by the policies will behave in certain ways and they will do so because they have certain motivations. For instance, a professional provider that is motivated to work based on altruistic preferences should be treated knightly, people who receive social benefit can be included as pawn and the consequences they have to be positioned as passive actors in the system.

Yet, Le Grand realized that strict policy will not be properly implemented because there is no pure motivation and agency like those terminologies. Therefore, he used so called “ robust strategies” to express strategies or institutions that are robust to whatever assumption is made about the human motivation (Le Grand 1997). The strategies are based on the assumption that we can convert knaves into knight as well as empowering people to become queen. Although the idea is difficult in implementation, the search for policies that are robust to different assumptions concerning human behavior is not impossible one.

## Patient – health care provider relationship

There were few studies observing patient and health care providers relationship in the developing countries. For instance in Egypt, a study conclude that family planning consultations were associated with greater satisfaction and continuation on therapy (Tawab 1995). Overall, patients in developing countries generally play a passive role in medical consultations (Tawab 1995, Roter, et al. 1998, Kim, et al. 1999). Many factors support the limited participation of patients such as differences in medical knowledge, educational level, socioeconomics status in which providers are perceived in higher social standing than patient, and an argument of conventional model of provider centered care that contribute to more unequal relationship. A study in Indonesia described that providers’ information giving, providers’ facilitative communication, providers’ expressions of negative emotion, client education level and culture influence are factors significantly associate to patient-provider relationship. The study reccomended combination of provider training and client education especially on key communication skills could increase the patient participation on health care consultations (Kim, et al. 2001).

Basically, there are three types of patient and provider relationship (Folland, Goodman and Stano 2007). First is the medico-technical model that assumes patient demand is determined by the providers based on objective needs. In this model, health care providers act as perfect agent on behalf of their patient and they know with certainty the results of their decisions. Patients demand is completely (price) inelastic because they are shaped by their medical needs. However, there is substantial empirical evidence that the above assumptions are violated in the practice, for example, doctors may not represent the perfect patient’s agent because sometimes they experience conflicting interest. Doctors also often do not know with certainty the effects of medical treatment. Another is that patients do not have uniform preference even if they are well informed. As the results patients are not sensitive to price and income and tend to find the trusted providers

Second model is the neo-classical model that assumes patient demand is determined by utility maximization subject to a budget constraint. In this model, patients are sovereign and rational, they are able to maximize utilities and knows with certainty about their decision to consume a treatment. Patients have predetermined and ordered preferences to select their providers. Medical need is not the only the determinants for patient preferences, patient want, income, education, prices of other goods etc are also determining factor that construct the decisions of patient. Critiques on this model is that patients are not always sovereign and rational, in fact they are mostly rely on providers’ judgment. As the consequences of asymmetric information, patient do not have sufficient predetermine and ordered preferences regarding to medical and they mostly do not know with certainty the result of their consumptions decision.

The third model is the imperfect agency model which assumes a condition of partly patient initiated and partly provider initiated. In this model, providers act as imperfect agents for patients in which they can pursue their own interest (income, status etc) alongside patients’ interest. As the results, overprovision and underprovision of care may occur depends on the provider’s income and incentives. In addition, different payment systems are likely to create different outcomes.

## The context

## Political and Law system in Indonesia

Indonesia adheres democracy as the main ideologies on the political arena. Freedom of expression is the vital basic rights in democracy. It is a tool to make democracy work because involving individual or society as a whole to participate and take responsibility in democracy. As a democratic country, Indonesia guarantees the freedom of expression and speech through its constitution, article 28 of Indonesia constitution enacted in 1945. To reinforce the implementation, Indonesia enacted several acts such as Act no. 39/2009 about human rights and ratified International Covenant of Civil and Political Rights through Act no. 12/2005. As a result, the rights of expression and speech have been the fundamental rights in Indonesia political and law system because it is assured and protected by the constitution and other law instruments. The violation against these rights does not only mean contravene the law but also infringe citizen constitutional right. Despite of that, Indonesia is a kind of young country in newly political system. The pure application of democracy and good governance have just established since the political reform in 1998. The reform triggered the civil clash which then impeached the former president. From that moment, Indonesia started to enjoy new political life and reforms on multi-sectoral fields.

## Social condition in Indonesia

In Indonesia, local cultural norms strengthen the daily social life. Two basic principles that influence the way people interact which conflict avoidance and respect (Suseno 1987). The people of Indonesia often keep maintaining social harmony and choose to avoiding conflicts in communication style. This respectfulness often do not recognize the context of situation, and may extend to important communication process like between patient and health care provider. Patient much respects provider as people with higher status and that emphasizes the authoritarian model. Patients mostly aware of their lower hierarchical position in the communication process and put back decisions to provider for showing respect and avoiding conflict. Thus, the cultural context hinders patient from voicing disagreement, concern or confusion regarding providers decision. This typical cultural norms should be taken into account if we want to discuss the minor role of patient in the health care system.

## Health care system in Indonesia

Health care system in Indonesia is on the basis of tiered system, like many countries, the ministry of health puts more responsibility of health care program to local health department. This policy was taken to anticipate the decentralization policy that has been applied since 1999. In this circumstances, the ministry of health only establish main program in the national level, while the local health department as the branch of the ministry of health in the municipality is the executor of the program and it may modifies the program depending on the local approach.

Health care funding mostly comes from the central government as the proportion of national budget for the health care program (MoH Indonesia 2007). The central government subsidies the implementation of program in the provincial and district level while the lower level is the direct responsibility of provincial level. The provincial and district also receives financial support from the local government that is obligated by the decentralization law. In Indonesia, almost 84% of the citizens are paying out of pocket which means they pay directly after they get the treatment. Insurance is only applied for government worker, military forces and people that applies for private insurance. The contribution of insurance is so little in the health care funding because most of the source comes from the allocation of national budget.

## Patient Organization in Indonesia

The first and the largest of consumer organization in Indonesia is YLKI stands for Yayasan Lembaga Konsumen Indonesia (The Indonesia Consumer Organization), a non profit and independent organization. In general, it does not only represent the patient interest but also wider terminology, “ consumer” as the individual or society that enjoys services from the provider, including health care services. YLKI was established in 1973 by the group of woman who was concerned with the empowerment of people and domestic product (YLKI 2009).

Recently, YLKI has been widely popular for its achievement to advocate Prita Mulyasari’s case. However, Prita’s case is not the only “ big bang” case that surprising the entire nation. Before Prita, on May 2009, YLKI took legal action against the President of Indonesia in case of tobacco control. YLKI pushed the President to ratify the Framework Convention on Tobacco Control (FCTC) which has already been ratified by 161 countries, YLKI also forces house of representatives to approve the act on tobacco which has been drafted for years. To enforce this legal complaint, YLKI acquired 1 million voices and signatures from people. However, the case was not as smooth as Prita’s case because so many conflicts of interest in the tobacco control that one of it involves cigarette companies which contributes high income for the countries. As the result, the case was suspended and the approval of the act faced deadlock.

Since the establishment in 1973, YLKI has set its position as the public server that received complaints regarding the poor government services, malpractice and consumer loss. The pattern of services moderately changing towards advocation and legal support when in 1997, YLKI for the first time submitted class action against the Indonesia Power Company for electricity black out across Java-Bali. Although YLKI failed on the trial, public aware the crucial role of YLKI as the representation of consumer interest. Having struggled for a consumer protection act, YLKI was successful to push the house of representatives to approve the Act of Consumer Protection in 1999. Afterwards, under the new act, YLKI actively involved in public advocation and consumer protection including a positive result on decreasing the telephone tariffs that was achieved in 1999.

## The Case

In 2008, Indonesia had been surprised by the tragedy of a patient named Prita Mulyasari. She was an ordinary housewife and mother of two children that had been arrested for defaming an international hospital via online complaint. Her complaints was about the misdiagnose and poor treatment at Omni International Hospital which was soon distributed through mailing lists. Once the complaint publicly noticed, the Omni International Hospital responded by filling a criminal complaint and civil lawsuit against Prita. Prita was then arrested on May, 2009 by the Banten Prosecutor’s office. She was charged under the criminal code of defamation of Information and Transaction Act No. 11/2008 which actually has not been enacted yet for this case. Prita had to face maximum six years of imprisonment and fines up to IDR 1 million as the result of her straightforward complaint to public (Gunawan 2009).

The decision of the court fueled public anger and demanded for legal reform including the release of Prita from the detainment. Prita was then released from detention on June 3 but still remained under city arrest due to “ humanitarian reasons (mother of two children)” before facing court on June 25 for her criminal defamation trial. In the local court, Omni international hospital withdrawn its criminal claim to Prita but still appealed for the material charge of IDR 204 million (US$ 20. 500). In the obligation of paying the material claim, Prita and her supporting team (including YLKI) did fund raising which was popularly known as “ Coin For Prita”, while her attorney team struggled for the case until supreme court level. Only in half of month since the program started, the donations from across country has reached fantastic number 650 million rupiahs. At the supreme court, Prita was freed from any charges including material claim and she got her name rehabilitated. Knowing the facts that public supported Prita, Omni international hospital cancel their effort to counter sue Prita and finally Prita enjoys her common life as housewife and mother of two children (Gunawan 2009).

## Discussion

The traditional life norms which based on conflict avoidance and respect might be plausibly used as prejudice to analyze the changing pattern of patient organization role. As this study finds that medico-technical model is generally applied in the patient-provider relationship, the social life norms may contribute to the continuation of this practice. The existing norms give opportunity for doctors to abuse the relationship and maximize their benefits. Why ? by avoiding conflict and respecting the behavior of the doctors, the patient will lose the ability to criticize the decision of the doctors and as the result keep positioning doctors in paternalistic path, the “ untouchable” domain where the decision of a doctor has to obeyed for the sake of the patient. Under this circumstances, doctors may play authoritarian role where he can maximize the opportunities for their benefits. This analysis maybe incorrectly evaluate the whole principle of medico-technical model because we cannot generalize the behavior of doctors as purely knave who always importance their self preference. However, the Prita’s fact shows us reasonable notion that the abuse of ethical code of doctors maybe turned out if the patient does not empower himself becomes an “ active” patient (Barbot 2006).

By highlighting Prita’s case, we might learn that the quality and quantity of patient’s relationship with health care provider is critical to improve the health outcomes and manage discomfort of patient’s problem. For providers, it is always an obligation to encourage patients to explain their condition. In today’s modern care, providers should not perceive themselves in authoritarian role that traditionally deliver treatment plan without further consulting with the patients. Providers also have responsibilities to observe patient willingness and demand irrespective of their professional knowledge and skills. This study notices that on Prita’s case, the international hospital did not adequately accommodate the aspiration of Prita, it tends to disregard the complaint of patient therefore Prita was discovering another way to express her feeling which later made the case even worse.

Instead of evaluating provider’s side, patients should also learn to improve their mindset on how the relationship works. This study does not recommend that traditional social norms must be radically changed to build an “ active” patient. We could make adaptation on the behavior of the patients. Patients who are able to express their needs, symptoms and interests may supply useful information for providers to determine their diagnosis and treatments. Clients who actively ask for information and clarification from providers may generate better understanding about their condition and equipped with sufficient knowledge to determine their decisions therefore they have more confidence and greater commitment to the therapy. Another consequences, that they may achieve higher levels of self-satisfaction and the most important one is better compliance. One of the key to achieve this “ new’ pattern is involving patient organization as the bridge to fill the missing link in the patient-provider relationship as well as to empower patient to understand more about their rights and crucial role on this situation.

The enactment of consumer protection act in 1999 is a perfect instrument for supporting the issue of patient organization role. By applying the act, patients, individually or collectively have stronger power and position in the health care system. Using Le Grand theory, the act is a “ robust policy” that may empower patient to become a queen on the system. Patients now are no longer taking part as passive victim but they have another option to be responsible for their lives by selecting the appropriate provider and the most importance one, in addition possessing law power if they are mistreated by the providers. This notion is also similarly applied for the health care providers, they cannot dominate the relationship because the policy set the doctors in equal relationship with patient. In Le Grand theory, the providers cannot work only based on self preference motivation. They have to incorporate altruistic value in their practice, more knightly sense because the demands are clear that patient is no longer assumed as the object of the treatment, otherwise they will face lawsuit or civil clash just like Prita’s case.

YLKI, as the largest patient representation in Indonesia aware to this transitional situation. Therefore, they are transforming from just a patient educator toward mediation and advocation of patient’s problem. This transformation were getting improved after political reform in 1998 which one of important outcome is the assurance on the freedom of expression. This shifting role would be impossible to happen in the past because the political and law atmosphere were not supporting this recognition. The centralistic government in the past was designing the health care system “ top-down’ without further requiring advice from other parties include patient organization. Although YLKI was exist, it constituted minor role in the health care system where it only represents common sense public issue. None of phenomenal record was made (or even successful in the practice), not yet until the reform in 1998.

After the political reform, the government started to realize the role of YLKI on the health care system. Linier to what Le Grand calls a queen, YLKI was then considered as the active participant of the system. However, this study underlines that the term queen for YLKI during the period was actually “ an incomplete queen”. Why ? Although YLKI was known as one of the actors in the system, their access on the system was remain the same. YLKI had to struggle alone to propose a policy or sounding the public interest while its substantial role was underestimated by the government until the government requested YLKI’s advice. As the consequences, YLKI was like an advisory board that was allowed to give recommendation after being ordered by the government. Seemingly, they did have the power but they did not have the access to channel the power except the government accommodated them in the decision making.

This situation continued until Prita’s case erupted and radically change the political configuration. The success on advocating Prita was a blessing for YLKI to play better role in the system. Nowadays, YLKI is much braver to “ face to face” with the government as well as advising the appropriate policy for the patient problem. The current role of YLKI is obviously described by Helderman as the type of associational order where YLKI as public representation is involved in the policy making process in health care system and it equals to government as the facilitator of the state. After the Prita’s case, the government perceives YLKI as a substantial actor on the health care system and both of YLKI and governments are sitting together to negotiate the possible policy for resolving or improving the patient interest. This radical movement makes YLKI is an influential participant on the system with more access to determine how the policy works for the benefits of the patients.

Prita’s case does inspire a new wave of patient-provider relationship. In fact at the moment, patients posses a powerful body that protects their interest. If patients experience poor services they will directly know where they have to report their problems. Learning from Prita, health care providers become more sensitive to the patients, thus they are trying to deeply understand the position of patient. However, on the long run, YLKI should concern to the continuous empowerment of patient because current situation is a fragile “ honey moon phase” where public were shocked by the euphoria of Prita’s victory while actually their fundamental knowledge on health and patient right is very weak. This is a home assignment for YLKI so in the future, YLKI will no longer be considered as “ public complaint board” but more specific on “ patient promotion board” that synergizing mutual relationship of patient-provider within good framework of health care system (Rabeharisoa 2006).

Last, surely this study cannot be escaped from the limitation. The limitation of this paper is that generally based on the