Donor Organ Shortage Crisis: A Case Study
Review of an Economic-Incentive System

A Dissertation to Complete the Requirement of Obtaining a Master Degree in Public Health (MPH) at the University of Liverpool.

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Declaration

No portion of this work was submitted to any other university or learning institution to obtain a degree or qualification or satisfy its requirements.

Signature: [signature]
Abstract

Introduction: Gross disparity between organ demand and supply created organ shortage - an important public health problem affecting organ transplantation. Organ supply system depends on altruistic non-coercive donation (ADS). Effective alternatives are sought to meet the desperate demand for organs and to combat organ trafficking. Feasibility of financial incentives is debatable; from medical, ethical and economic perspectives.

Background: In Riyadh, KSA, organ shortage is addressed by the Incentive-Based Procurement System (IBPS) applied by a Mobile Donor Action Team (MDAT). Incentives for donors' families and health workers resulted in three-fold increase in donation rate.

Aim: To provide a qualitative review of a four-year IBPS and to assess medical, ethical, religious, cultural and economic issues that have, and may impact the system and to make recommendations to the transplant community and health authority in KSA and elsewhere regarding the transferability of the system and areas for further research.

Method: Qualitative case study methodology was used utilizing two data sources: documents and interview. Document review was used to create a contextual chronological audit and to shape interview questions. Semi-
structured interviews were inclusive of all MDAT members using purposeful sampling. Findings were subjected to thematic analysis.

**Result:** Documents reflected the evolution of MDAT, thus providing contextual background to the case study. The in-depth interview suggested that IBPS is *the* reason behind the increase in donation rate. Moreover, and based on the opinion of MDAT members, IBPS has been acceptable from moral, ethical and religious aspects with high degree of professional satisfaction.

**Discussion:** Theoretical assumptions doubted the feasibility of IBPS. This real-life case study proved the contrary. The findings may only be applicable to the setting in Riyadh, KSA. Further research is needed to explore its transferability in other settings.

**Conclusion:** IBPS can be an alternative to ADS and should be piloted in different settings.

**Word Count:**

*Abstract:* 300 words.

*Dissertation:* 10999 excluding textboxes and appendices.

**Keywords:** Transplantation, economics, cadaveric, organ donation, incentives, financial.
Acknowledgments

My thanks and appreciation goes to the members of Mobile Donor Action Team (MDAT) in Riyadh, Kingdom of Saudi Arabia. Their dedication, perseverance, innovation and endless efforts in pursuing organ donation are the basis of this work.
List of Abbreviations and Definitions

ADS: Altruistic Donation System
IBPS: Incentive Based Procurement System
ICU: Intensive Care Units
KFSH&RC: King Faisal Specialist Hospital and Research Centre

This is the main tertiary health care center in Saudi Arabia. It performs close to two third of all transplant in KSA. It provides logistical, financial and administrative support to MDAT in collaboration with SCOT.

KSA: Kingdom of Saudi Arabia

It is a country in the South West of Asia occupying most of the Arabian Peninsula with a population approaching 25 million. Approximately, one third are expatriate from different ethnic groups, dominated by Arabs and Asians of Indian sub-continent and Far East.

MDAT: Mobile Donor Action Team

This is a team of doctor, coordinators and administrators. It’s supported and financed by KFSF&RC and function under the official umbrella of SCOT. It interacts with Riyadh ICUs through field work and provides service to accelerate the logistic of organ donation.

MOH: Ministry of Health in KSA

Riyadh: The capital of KSA with a population of close to five million.

SCOT: Saudi Center for Organ Transplantation

This is the official government organization responsible for organ procurement and monitoring of organ transplantation in the Kingdom of Saudi Arabia under which MDAT works.
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1. Introduction and Background

1.1 Introduction: End-stage organ failure is a major health problem leading to substantial social and economic losses. Since the 1950’s, organ transplantation made giant strides to become the standard of care with remarkable improvement in survival and quality of life for many patients (Morris, 2004).

1.1.1 Organ transplantation crisis: The number of patients on the waiting list as a consequence of the gross disparity between demand and supply, resulting in organ shortage, has become an important public health problem (Cherry, 2009). In most countries, the current organ supply system depends on altruistic non-coercive donation (Petersen, 2007). This model of volunteerism has been deficient in meeting an accelerated demand; a demand that is undermining the success of organ transplantation (Abouna, 2008; Tuttle-Newhall et al., 2009). The desperate demand for organs and the need to combat organ trafficking, transplant tourism and human exploitation (Scheper-Hughes, 2000; Shimazono, 2007; Budiani-Saberi and Delmonico, 2008) has resulted in the search for effective alternatives by many interested parties (Obermann, 1997; Wright, 2008; Lavee, 2009). One of these alternatives is the use of financial incentives to increase the rate of donation (Hippen and Matas, 2009). The debate continues about the
feasibility of such an alternative in particular as it relates to medical, ethical and economic dimensions (Delmonico et al., 2002).

1.1.2 Saudi Context: The first kidney transplant performed in the Kingdom of Saudi Arabia (KSA) was in 1979. Since then, organ transplantation in KSA followed the Western model in organ procurement and transplantation. The practice was brought about by the many scholars who received their training in Western institutions with an outcome comparable to international standards (Shaheen, 2004). Though the practice of transplantation continues to follow the modern Western style, organ donation has deviated from the classical altruistic model as practiced in North America and Europe. This change in the last few years was made in response to accelerated need for organs.

1.2 Background

1.2.1 The Benefits of Transplantation: Organ transplanting became a standard of care for end-stage organ failure (Morris, 2004). Patients, relatives, and society, suffers major consequences from end-stage organ failure leading to social and economic losses (disabilities, cost of treatment e.g. dialysis) affecting public health.
Survival benefit: The benefit side of organ transplantation includes patient survival, life-year gained (LYG) and quality of life. The table below shows the survival benefit of different types of organ transplantation.

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Liver</td>
<td>16.9</td>
<td></td>
</tr>
<tr>
<td>Kidney and pancreas</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>2.1</td>
<td></td>
</tr>
</tbody>
</table>

Quality of Life: Quality of life is measured in transplant patients using disease specific or generic instrument. An obvious example is the comparison of quality of life for transplanted patients and patient on dialysis. Klarman et al. (1968) used the anchored 0 to 1 scale to weigh survival time by quality of life with the generation of quality adjusted life-years (QALY). Laupacis et al. (1996) measured utility directly and found that the quality of life increased in renal transplant patients by 23% from
0.57 to 0.7. The European quality of life scale (EQ-5D) was also used in liver transplant patients. Bryan (1998) and Ratcliffe (2002) found that quality of life improved from 0.53 before transplant to 0.78 at one year.

**Economic advantage:** The economic advantage is illustrated by taking the example of renal transplantation; wherein the annual cost of transplant can be as low as 10% of that of dialysis (refer to the section 4.3, *Public Health Relevance*).

### 1.2.2 Organ Shortage:

The crisis of organ shortage is evident in the fact that less than 10% of patients on the waiting lists got transplanted resulting in mortality of at least 5-10% while waiting (Matesanz and Rudge, 2005). The discrepancy between the need and supply is illustrated below (Becker and Elias, 2007), which shows an accelerated demand for renal transplant in the face of a steady supply and a widening gap.

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**Figure 1. Kidney transplants:** Total number of transplants, living transplants, and total number of persons on the waiting list in the United States, 1990-2005.

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*Source: United Network for Organ Sharing*
1.2.3 Organ Shortage in Saudi Arabia: The population of KSA is around 27 million. More than 10,000 patients are on dialysis. There are no data on the deaths and waiting list. End-stage liver disease is common in KSA with estimated annual need for transplant of around 500 to 700 (SCOT, 2009). These facts illustrate the need for transplantation.

At the King Faisal Specialist Hospital and Research Centre (KFSH&RC), 50 to 70 patients are in the waiting list for liver transplants with mortality while waiting of 20% to 25% (SCOT, 2009).

The Saudi Center for Organ Transplantation (SCOT) is the official procurement agency which links the health care system to organ transplant center. It is responsible for organizing and promoting organ donation. From 1995 to 2005, the annual number of reported cases has been stationary at around 350 and not exceeding 400, (Figures 2, 3). The conversion rate (number of donor retrieved/number of donor reported) was as low as 5%. This is not due to the refusal of the family of the deceased to donate organs only but also due to logistical reasons such as failure to finish the documentation process (in up to 50% of the cases) or lack of appropriate donor medical management leading to loss prior to the stage of consent solicitation. The consent rate remains stable at 15% to 20%. The quality of organs was also issue since not all organs were accepted for liver
transplant (OLT) for example, contributing to the daunting problem of organ shortage (SCOT, 2009; Al Sebayel and Khalaf, 2004). The two illustrations below show the annual number of brain death cases reported, the number of cases with completed brain death documentation, the number of donors procured and finally the number of livers retrieved. They clearly demonstrate that only 10% to 15% of the total number of potential donor became actual donors.

**Figure 2.** Organ Donation in KSA (1995-2000).
1.2.4 The Creation of the Mobile Donor Action Team (MDAT):

With this background and because of the deficiency of the health care system in providing adequate supply of organs, one of the transplant centers (KFSH&RC) proactively tried to alleviate the problem of organ shortage, focusing on improving the dismal conversion rate by creating MDAT. Riyadh region was chosen for a pilot project (population of 4 to 5 million). This carried with it three challenges:

- Ethical issues in relation to conflict of interest when a transplant center tries to influence the donation process.

- Political issues between the official procurement agency (SCOT) and the transplant center (KFSH&RC) in terms of the definition of roles, authority and responsibilities.
• Administrative and financial issues related to operation.

The figure below depicts the change in number of actually retrieved donors as it compares to the rest of the Kingdom when the intervention was initiated in 2006. It shows also a comparison of Riyadh performance before and after the intervention;

**Figure 4.** Comparison of harvested donors between Riyadh and the rest of KSA between 2000 and 2009.

Breakdown of KSA by region is shown below. The conversion rate of Riyadh was approximately 25% compared to 7% to 12% for other regions.

**Table 2.** Brain-death cases reported, medically documented, families approached, consented for donation and harvested according to region, 2008.

<table>
<thead>
<tr>
<th>Region Name</th>
<th>Reported</th>
<th>Documented</th>
<th>Families Approached</th>
<th>Consented</th>
<th>Harvested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central</td>
<td>281</td>
<td>207</td>
<td>179</td>
<td>78</td>
<td>70</td>
</tr>
<tr>
<td>Western</td>
<td>83</td>
<td>42</td>
<td>26</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Eastern</td>
<td>49</td>
<td>30</td>
<td>21</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Northern</td>
<td>31</td>
<td>20</td>
<td>12</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Southern</td>
<td>57</td>
<td>30</td>
<td>16</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Outside KSA</td>
<td>32</td>
<td>30</td>
<td>28</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>533</strong></td>
<td><strong>559</strong></td>
<td><strong>282</strong></td>
<td><strong>118</strong></td>
<td><strong>105</strong></td>
</tr>
</tbody>
</table>
1.2.5 Literature Review:

Search strategy: Because the subject of search crosses boundaries between biomedicine, bioethics and economics; the researcher chose multiple database searching tools. These were Summon™ and Meta-lib™; both provided by the library service of the University of Liverpool. Summon™ provides a one-search box, which is as easy as the familiar Google search experience. It also provides relevance ranking and easy accessibility to full text articles provided by University of Liverpool. Meta-lib™ provided excellent access to public health database and allied health sciences. Finally, the Medline search engine was used for more extensive biomedical searches.

Keywords used were “organ donation” “cadaveric, cadaver” “economic and donation,” “incentives and donation,” and “financial incentives and organ and donation.” These produced numerous unmanageable publications. The search was then narrowed to the following terms: “incentives and don* and cadaver*”.

Meta-lib™ produced 470 hits and Summon™ 251 hits. Medline was searched through Refworks™. Their advanced search tool was utilized using the words “incentives and dono* and cadaver,*” which were used as descriptors that yielded 143 articles. These were screened and many were
not relevant to the search. The word “incentive” was then used as the title/primary word and yielded 15 relevant articles (all were retrieved except one which was not in English). The hits produced by the three databases were scanned and relevant articles were retrieved. Specifically, general articles about donation and transplantation were excluded. Articles concentrating on the use of incentives for living donors were limited to those with relevance to cadaveric donation. In-depth economic ethical and law articles lacking practical relevance as judged by the researcher were also excluded. Articles published in leading biomedical journals were particularly sought and judged as having more practical significance. This process yielded close to 70 publications, which were retrieved and about two-thirds of them were referred to in this work. The University of Liverpool provided Refworks™ as the reference manager of this research.

*Literature review outcome:* The focus of the review of literature was the studies on the actual use of incentives in the setting of cadaveric organ donation. No such studies were found. The use of incentives in the setting of living donor donation however was reported in the literature as the “Iranian model” in several publications (Bagheri, 2006; Ghods, 2006; Simforoosh, 2007; Einollahi et al., 2007). We then moved to search for any empirical data. Empirical data on the subject were based on quantitative
studies on public and professional attitudes towards the use of incentives in organ procurement (Boulware, 2006; Jasper, 2004; Jasper et al., 2004; Mayrhofer-Reinhartshuber, 2006) rather than studies on the actual practice of the Incentive-Based Procurement System (IBPS). These studies were scarce with a tendency towards rejection of financial incentives based on public and professional opinion. On the other hand, there is abundance of literature in debating the use of incentives based on theoretical assumption, economic modeling and pre-determined ethical postulation among clinicians, policy makers, economists, and ethicists. Debate among clinicians continues regarding the feasibility of financial incentives, particularly in two of the influential biomedical journals: *Transplantation* and *BMJ* (Tilney et al., 2009; Hippen and Matas, 2010; Tilney et al., 2010; Matas, 2008; Godlee, 2008). Earlier on, a panel of ethicists, organ procurement organization executives, physicians and surgeons forming the Ethics Committee of the American Society of Transplant Surgeons, unanimously opposed the financial incentives in the setting of cadaveric donation (Arnold, 2002). This opposition was based on the “violation of ideal standard of altruism and commercialize the value of human life by commodifying donated organs”. This is an echo of what was voiced by Titmuss in his seminal work “The Gift Relationship” in which he argued that
paying for blood donors will be discouraged and repulsed when it becomes a monetary transaction rather than altruistic (Goodwin, 2004, p.7).
The debate among clinicians seem to be moving towards a more relaxed attitude towards the idea of incentives, wherein discussion now is on details rather than the principle (Hippen and Matas, 2010).
Economists in general, not surprisingly, have a strong opinion for the use of incentives. The work of Gary Becker, a Nobel Prize winner, sparked a lot of discussion on the subject when he suggested an economic model based on financial compensation to solve the issue of organ shortage (Becker and Elias, 2007). He used economic connotations to argue that like any other economic systems composed of demand and supply, a market for organ donation can be brought to an equilibrium by increasing the supply of organs’ (from both cadaveric as well as living) procurement. Currently, donation of organs holds the price at zero and therefore organ shortage is inventible based on these economic principles. He and others (Waldly and Mitchel, 2006; Collins et al., 1997; Goodwin, 2006; Barnett et al., 2002) consider altruistic procurement policy a failure.
The notion of ownership of our bodies and therefore having the right to sell it is been used to argue for organ sale. The extreme of this argument is
voiced by calling the ban on selling organs an act of “paternalism at its worst form” (Savulescu, 2003).

The counterargument against this approach was voiced by the report of the Institute of Medicine, USA on organ donation (Childress and Liverman, 2006), which argued against financial incentives and market for organs based on the assumed technical difficulties in establishing a market for such heterogeneous and perishable “good” with transactions being done under pressing and difficult circumstances than that of the familiar commercial transaction. Besides, this approach brings about the issue of the commoditization of a human body (Childress and Liverman, 2006); a viewpoint supported by Das and Lerner (2007).

The ethical framework in organ procurement determines organ procurement policy. The ethical principles underpinning the actions pertaining to organ procurement are concerned about three premises: utility, justice and autonomy at individual and societal levels. The tension between these three premises is based on a myriad of ethical theories for the right action as outlined by Veatch (2000, p.28) in his book, Transplantation Ethics, and summarized as follows:

Hippocratic Ethics: Adopted since ancient Greeks; this is the classical ethical system of health workers. The core value of the Hippocratic ethics
rests on the pledge to “benefit an individual patient”. The underpinning values are “individualism” and “consequentialism” (beneficence), which is opposite to social utilitarianism (Marxism); a consequence-oriented value (consequentialism) for society rather than individual. The latter is the ethical framework for what is called the “routine salvaging” in organ procurement, as proposed by Jesse Dukeminier and David Sanders in 1968. They argued that, “no harm is inflicted by using cadaver without formal permission since there is a net gain for the society by saving the needing patients.”

*Virtue Ethics:* Rooted in the classic Greek philosophy, its focus is personal trait. Some consider feminist theory of medical ethics a modern variant of the virtue ethics. The virtue of benevolence is considered the essence of the donation model in organ procurement and virtue ethics may serve as its ethical framework. (Bjorkman, 2006).

*Deontological Ethics:* This is based on Immanuel Kant’s ethics, which takes rightness or wrongness in consideration rather than merely consequence. This means that autonomous choice of a patient or donor overrides the consequence of the action (e.g. donation). Its focus is “respect for persons” especially as it relates to their autonomous life plan. The respect of body
integrity continues after death, which is the basis of the modern donation model in organ procurement.

The contemporary bioethical theory falls in the middle of a continuum of consequentiality and deontological dichotomy. The influential work of Tom L. Beauchamp and James Childress’ *Principle of Biomedical Ethics* is an example of such theory, which balances consequence with that of the virtues of fairness and autonomy. Veatch (2000) summarized the mainstream theories of right action into the modern normative moral theories that can have a character of one of the two dichotomies: individualist-society and consequentialist-deontological as shown:

<table>
<thead>
<tr>
<th></th>
<th>Individual</th>
<th>Society</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consequence</strong></td>
<td>Hippocratic</td>
<td>Social utilitarian</td>
</tr>
<tr>
<td><strong>Deontological</strong></td>
<td>Respect for Person</td>
<td>Egalitarian</td>
</tr>
</tbody>
</table>

Ethical approaches in organ procurement can also be based on religions, especially in those societies or individuals who are committed to a religion rather than secular perspective. The three main religions: Judaism, Christianity and Islam, promote social justice and care of those who are in need. Organ procurement is either allowed or encouraged to achieve these goals (John Paul II, 2001; El-Shahat, 1999).
1.2.6 Summary: The background and literature review can be summarized in the following points:

- Organ transplantation has a substantial impact not only on the patients’ well-being, but also on health economics and public health.
- The failure of the current altruistic model of organ donation led to the search of other alternatives.
- The argument for paying donors is based on a consequential approach that rests on the assumptions that if people choose not to donate then patients die because of organ shortage and if we provide incentives, then the donation will be higher and consequently, more lives will be saved. This assumption is empirical and needs to be proven, which is what this work tries to do. The strong motive is “we should not let people die queuing for organs when there are alternatives” (Bjorkman, 2006).
- Proposal to increase organ procurement by the institution of financial incentives has been rejected based on theoretical arguments.
- No empirical data on the subject, except those of public and professional surveys, which are mostly quantitative.
- Organ scarcity in the KSA led to pilot a project of IBPS, resulting in a substantial increase in the number of donors. This is the first
empirical study to evaluate the use of financial incentives in the setting of cadaveric organ donation.

1.3 Research Question: What are the outcome, feasibility and transferability of employing an incentive-based system on cadaveric organ donation in KSA?

1.3.1 Aim and Objectives: Using a case study, the aim was to provide a qualitative review of a four-year, incentive-based, organ donation system in order to refine the current system and assess transferability to other settings. This took place in the setting of cadaveric organ transplantation in the Riyadh region of KSA. Specific objectives were:

1. Review program documents of the last four years in order to provide a chronological evolution of the organ procurement, incentive-based system and identify barriers, facilitators and lessons learned from the process.

2. Utilize key informant interviews to fill in the gaps and confirm the results from the document review, further assess medical, ethical, religious, cultural and economic issues that have, and may impact the program and also assess issues associated with transferability of the system to other settings.
3. To make recommendations to the transplant community and health authority in KSA regarding the transferability of the system and areas for further research.

1.3.2 Epistemological Framework: An insight to epistemology is very influential on the outcome of the research (Green and Thorogood, 2004, p.7; Bowling, 2002). The impact of IBPS on organ donation depends on the position of the members of MDAT and the families of the deceased towards the idea; it follows that there is no neutral reality to justify positivism as suitable epistemological framework underpinning this work. Reality about the subject seems to be embedded in the social, cultural and religious beliefs of the health workers, MDAT members and the families of the deceased. As observed by Schicktanz and Scheeda (2009), perspectivism has considerable relevance in organ donation. This brings the research to a constructionist approach shaped by this triad (Green and Thorogood, 2004, p.12). This is typical of social science research as opposed to natural science, which relies on a “value-free” rather than a “value-laden” stance which is uncommon in the field of transplantation since organ donation and transplantation is within the realm of a health worker whose training is dominated by the epistemology of positivism.
In this work, the researcher was solely in charge of both the data collection and the interpretation. The environment is familiar as well as the personalities. The researcher is a transplant surgeon and is in charge of the liver transplant program at KFSH&RC, which indirectly supports the work of MDAT. He has work relations with SCOT and members of MDAT. This may create a situation of deep involvement that may lead to a bias. At the same time, keeping a distance may lead to missing important data. Patton (2002) suggested a stance in the middle and called it “empathic neutrality”. He also suggested that throughout the process, the researcher should be aware of reflexivity not only of the researcher himself, but also those who are researched and even the audience. In this work, the positionality of the researcher and its potential influence on the research was noted as well as that of participants.
2. Methodology

2.1 Study Setting: The study was based on the IBPS practice of MDAT members in Riyadh, KSA as reflected mainly by documents and in-depth interviews. It was conducted within the premises of KFSH&RC by the researcher.

KFSH&RC is a governmental tertiary care centre. It provides multi-organ transplantation for patients referred from healthcare facilities nationwide. The desperate need for organs led KFSH&RC to proactively join SCOT in the effort to enhance organ procurement and alleviate the organ shortage crisis.

2.2 Research Design: The research question was approached through a case study of the organ procurement system in Riyadh. This approach was deemed more suitable to answer the research question based on the fulfillment of the features of case study research as proposed by Yin (2009), who defines case study as:

“[A]n empirical inquiry that investigate a contemporary phenomenon …..within its context …. [B]oundaries between phenomenon and context are not clearly evident.”
The study is an empirical inquiry of organ procurement in Riyadh based on the use of incentives to solve organ shortage crisis, which is a contemporary phenomenon. Prior theoretical propositions were laid by many authors to solve the problem of organ shortage (see literature review). Another feature of this case study is its real life context which explores the real life situation of organ shortage and how that was addressed using incentives to intervene. Case study has the distinctive feature of the inseparable link between the phenomenon and the context (in this research: IBPS and MDAT). Other features include its reliance on multiple evidences to explore multiple variables of interest (Yin, 2009).

The methodology of the research was a qualitative case study based on two data sources: document analysis and interviews. Qualitative approach was chosen to be able to explore socially constructed opinion and beliefs which influence the practice and outcome of IBPS. Most of the empirical studies on the subject were based on quantitative surveys, which the researcher considered too superficial in addressing the research question. Document analysis provides understanding of the research context. In-depth interviews were conducted using a semi-structured interview-guide that was developed using themes emerged from document analysis. The guide was useful to keep the interview on track focusing on the research
question. Nine interviews were conducted with MDAT members, administrators and a key informant.

2.2.2 Document Collection: Documents are very valuable tools in understanding the evolution of a case and to get to know what people did or valued in a chronological order. Documents describe the situation explicitly as it occurred, have stronger validity and therefore can be a very efficient source of qualitative data (Green and Thorogood, 2004, p.155). Its weaknesses include selection, reporting bias and problems with access and irretrievability (Yin, 2009).

Hancock and Algozzine (2006) listed questions to be asked before accepting documents, as suggested by Clark in 1967. These questions include its origin, history and how it was obtained. Inquiry about authenticity, integrity, accuracy and appropriateness also needs to be addressed. Finally, one needs to explore the intention of the document, the source of its information and availability of other sources to confirm its content.

A written permission from the manager of MDAT was obtained (Appendix 8) to access the documents obtained from the filing system of MDAT, both at KFSH&RC and SCOT. The documents were scanned by the MDAT secretary and stored in the researcher’s personal computer, which was
password-protected and arranged chronologically. The documents were then classified into the following categories:

<table>
<thead>
<tr>
<th>Document Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative</td>
</tr>
<tr>
<td>Training and development</td>
</tr>
<tr>
<td>Logistical</td>
</tr>
<tr>
<td>Budgetary and fund raising documents</td>
</tr>
<tr>
<td>Documents pertaining to incentives for members of MDAT and ICUs personals</td>
</tr>
<tr>
<td>Documents pertaining to donor and donor families</td>
</tr>
<tr>
<td>Reports and evaluation</td>
</tr>
<tr>
<td>Government documents and legislation</td>
</tr>
</tbody>
</table>

Relevant documents describing the evolutionary process of MDAT, the role of incentives in this process and the reaction of different stakeholder towards IBPS as practiced by MDAT members were included. Routine administrative documents such as contractual issues and leave requests were excluded. The researcher’s knowledge of the background of MDAT was influential in this selection. One hundred and sixty-seven documents were collected and sixty-five were found to be useful based on the above-mentioned criteria.

A list of questions to be answered when gathering information from a document was proposed by Hancock and Algozzine (2006). This list was modified to develop an observational guide for the selected documents based on the research question, aim, objectives and the knowledge of the
researcher of MDAT background. Each document was scrutinized using the observation guide in a tabulated format. These tables were then compared within each document category and in-between categories. This process produced themes and sub-themes used to gain understanding of the IBPS and generate questions to be used in the in-depth interview.

**Table 3.** Document observational guide.

<table>
<thead>
<tr>
<th>Document type and date:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Document Category</td>
<td>Source</td>
</tr>
<tr>
<td>Evolution of MDAT and Structural changes.</td>
<td></td>
</tr>
<tr>
<td>Evidence of increase in donation rate.</td>
<td></td>
</tr>
<tr>
<td>Evidence of the use of incentives.</td>
<td></td>
</tr>
<tr>
<td>Western training for MDAT team.</td>
<td></td>
</tr>
<tr>
<td>Transferability.</td>
<td></td>
</tr>
<tr>
<td>The use of financial incentive for the families and medical teams</td>
<td></td>
</tr>
<tr>
<td>Ethical basis of the use of incentives</td>
<td></td>
</tr>
<tr>
<td>Follow-up</td>
<td></td>
</tr>
<tr>
<td>Emerging themes</td>
<td></td>
</tr>
</tbody>
</table>
2.2.3 *Interview*: Interview was chosen as a methodology to answer the research questions (Green and Thorogood, 2004, pp. 79-106). Yin (2009) regarded in-depth interview as an important source of case study information considering its insightful, provision of casual inference and

<table>
<thead>
<tr>
<th>Type of document</th>
<th>Theme</th>
<th>Potential question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statistical tables Performance reports</td>
<td>Increase in donation rate</td>
<td>Was there an increase? And Why?</td>
</tr>
<tr>
<td>Records of families-coordinators interviews Financial document</td>
<td>Use of financial incentives</td>
<td>Are financial incentive used? What is the effect?</td>
</tr>
<tr>
<td>Regulation, legislation, religious declaration.</td>
<td>Ethical basis of use of incentives</td>
<td>What are the moral and ethical issues?</td>
</tr>
<tr>
<td>Memo of understanding, agreements (SCOT&amp;KFSH) and administrative documents</td>
<td>Evolution of MDAT</td>
<td>For the researcher to understand the background MDAT</td>
</tr>
<tr>
<td>Evidence of training, certificates</td>
<td>Western training of MDAT member</td>
<td>How does Western training shapes the view about incentives</td>
</tr>
<tr>
<td>Recommendation and future planning</td>
<td>Transferability</td>
<td>Is the system applicable to other settings</td>
</tr>
<tr>
<td>Policies and procedures</td>
<td>Structural changes</td>
<td>How do a structural changes contributed to the increase in donation rate.</td>
</tr>
<tr>
<td>Administrative memos</td>
<td>Incentives for medical teams and MDAT</td>
<td>What is the degree of satisfaction with the process?</td>
</tr>
</tbody>
</table>

Table 4. Document themes and potential questions.
focus. The typical weaknesses are bias and reflexivity. It was considered most appropriate in this research since participants are small in number and homogenous with the likelihood of content convergence. The power balance between the interviewer and interviewee can influence the outcome. The shift of power towards the researcher was balanced by a friendly introduction before the interview, informality and trying to make the interview more of an idea exchange rather than interrogation.

**Ethical approval:** Ethical approval for the study was obtained from the University of Liverpool Ethic Committee (Appendix 6). Written permission to conduct the study was obtained from Ministry of Health, SCOT and KFSH&RC (Appendix 6).

The purpose of the research was explained to all participants. They were informed that the interview would be recorded and then transcribed. They were assured that the information provided would be accessed by the researcher only and that anonymity would be protected for the participants. They were also informed that the information provided would be used only for the purpose of this project. The tapes and transcripts and any other relevant information would be stored and locked securely in the researcher’s office and stored for a maximum of two years; after which, all transcripts and tapes would be destroyed. They were asked to read the
information sheet and then sign the UoL consent form (Appendix 5). The interview took place in an office and was recorded and transcribed by the researcher. Only the personal computer of the researcher was used, which was password protected.

**Piloting:** A pilot interview was first conducted with the least experienced member of the team, which led to modification of the questions (avoiding repetition) and technique (watching for time and interruption once participant repeat same ideas). Also, the technique was improved to try avoiding leading, interrogation and deduction, which are common in clinical interviews that the researcher, being a clinician, is accustomed to (Hanson and Neuhauser, 2003). The interview questions were not modified but the technique was changed to more of an exchange of ideas with the participants.

**Sampling:** Sampling was purposeful (Patton, 2002) and inclusive of all members of the MDAT team who are employing incentives in the setting of cadaveric organ donation in Riyadh, including the two administrators and Director of SCOT. The studied group is the only group employing IBPS in this setting, which left no choice except using MDAT members as the sole sample. Because the number of the team is small, this approach was manageable. The key informant was chosen based on his in-depth
knowledge of the donor situation in KSA. Below are the general demographics of respondents.

Table 5. Demographics of the participants.

<table>
<thead>
<tr>
<th>Code</th>
<th>Age/Sex</th>
<th>Position</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA</td>
<td>Male/36</td>
<td>Sr. coordinator</td>
<td>Administrative. Short training courses on donor coordination. Hands-on Experience</td>
</tr>
<tr>
<td>RS</td>
<td>Female/32</td>
<td>Sr. coordinator</td>
<td>Administrative. Short training courses on donor coordination. Hands-on Experience</td>
</tr>
<tr>
<td>MA</td>
<td>Male/28</td>
<td>Coordinator/Technician</td>
<td>Technical. Hands on experience</td>
</tr>
<tr>
<td>AB</td>
<td>Male/37</td>
<td>Physician</td>
<td>Medical. Training courses</td>
</tr>
<tr>
<td>AAB</td>
<td>Male/34</td>
<td>Physician</td>
<td>Medical</td>
</tr>
<tr>
<td>BB</td>
<td>Male/45</td>
<td>Nurse/Coordinator</td>
<td>Nursing. Field Experience</td>
</tr>
<tr>
<td>TA</td>
<td>Male/42</td>
<td>Administrator</td>
<td>Administration</td>
</tr>
<tr>
<td>AN</td>
<td>Male/49</td>
<td>Administrator</td>
<td>Administration</td>
</tr>
<tr>
<td>FS</td>
<td>Male/54</td>
<td>Administrator/</td>
<td>Medical and Administration</td>
</tr>
</tbody>
</table>

Data collection and management: Short interviews (30 to 45 minutes) using a semi-structured interview-guide were conducted with the MDAT six-member team (direct implementers of the incentive-based donation program in Riyadh); two interviews with the administrators working with MDAT (focus on management and administrative issues); and one interview with the Director of the National Donation Organization to explore the transferability to other regions of KSA. The questions in the interview were based on the review of the documents as shown below:
The interviews were conducted in Arabic since it was the first language of most respondents. It was felt that using the respondent’s native language would be more accurate and would potentially produce a richer interview. The researcher translated the Arabic recording into English by listening to the tapes repeatedly and translating the content one sentence at a time. Once the translation was complete, the transcript was reviewed. Transcripts were then shown to the respective participant for accuracy of the translation. For confidentiality and anonymity reasons, it was decided that the participants

<table>
<thead>
<tr>
<th>Table 6. Interview guide summary.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are the reasons of increase in organ procurement?</td>
</tr>
</tbody>
</table>
| 2. Describe the role of incentives in this increase | What kind of incentives?  
| | Who receives them?  
| | Which part of the process is effective? And with whom?  
| | What are the problems?  
| | What other alternatives?  
| 3. Why IBPS morally wrong/right? | What are the benefits?  
| | What is the harm?  
| 4. What are the medical advantages? |  
| 5. What are the ethical issues? | What is the influence of on the practice?  
| 6. What are the economic advantages/disadvantages? |  
| 7. Why IBPS permissible/not from different aspects? Social, religious…etc. | Influence on practice  
| 8. What are problem or opportunities in applying it to other setting | Rest of KSA, Middle East and West  
| 9. What type of incentive more effective? |  
| 10. What is the degree of satisfaction? | How does it affect your work?  
| 11. Any other concern/comment? |  

The interviews were conducted in Arabic since it was first language of most respondents. It was felt that using the respondent’s native language would be more accurate and would potentially produce a richer interview. The researcher translated the Arabic recording into English by listening to the tapes repeatedly and translating the content one sentence at a time. Once the translation was complete, the transcript was reviewed. Transcripts were then shown to the respective participant for accuracy of the translation. For confidentiality and anonymity reasons, it was decided that the participants
themselves would do the verification of the accuracy of translation rather than an external reviewer.

2.2.4 Analysis

**Thematic content as a framework for analysis:** After the interview transcriptions were completed, thematic content analysis was performed. Word processing software was used to create tables for each participant’s interview with line numbering, content and emerging theme fields (Appendix 2). The main themes were simply coded in separate tables so that ten themes emerged from the interviews (Appendix 3). Each table contained a field for the participant identification code (ID) and another for the sub-themes so that it is visually easy to sort, compare, group and spot deviance of the sub-themes among different participants. The researcher considered thematic content analysis (Schwandt, 2007; Green and Thorogood 2004; Patton, 2003) as the most appropriate method of analysis for the following reasons:

- The study is small scale (small number of participants) with the aim of identifying simple themes rather than complicated social phenomena, which may require for example, going back and forth between data and theory (Strauss, 1987).
Methodology used (in-depth interview) and the nature of data produced (simple themes) makes other approaches for analysis less appropriate (grounded theory or framework analysis).

The nature of data is more suitable to cut and paste approach in order to compare themes, classify them and come up with an interpretation.

In general, the method of choice for health studies that do not need in-depth probing is thematic content analysis; the study above is in this category.

The number of themes and their classifications were simple and therefore did not need a complicated analysis, which goes along with the experience of the researcher.

Validity and reliability: Appraisal of research determines its credibility depending on validity and reliability. In qualitative research, this is more problematic and depends on constant comparison while doing thematic analysis and identifying emerging themes, which was adopted in this work. Irregularities and deviant cases were sought. Triangulation was used to some extent when comparing the content of the document to the themes that emerged from the in-depth interview. Particular attention was paid on reflexivity and positionality Arber (2006), based on the familiarity of the
researcher in the field of organ transplantation and the personal knowledge of the participants. Audit trail accessibility was not possible for confidentiality reasons. External review was not applied for the same reasons. The credibility of the research determines its degree of dependability and confirmability and therefore increases the chance of transferability, (Lativa and Jacoby, 2002).

3. Results

The number of document scrutinized was one hundred and sixty-seven. Sixty-five were thoroughly examined and categorized based on time line and content, (Appendix 1).

<table>
<thead>
<tr>
<th>Table 7. Summary of category, themes and sub-themes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
</tr>
<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>Administrative</td>
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<tr>
<td></td>
</tr>
<tr>
<td>leadership</td>
</tr>
<tr>
<td>Rewards and compensation</td>
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<td></td>
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<tr>
<td>Training and development</td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Logistical</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Category</td>
</tr>
<tr>
<td>--------------------------------</td>
</tr>
<tr>
<td>Budget and fund</td>
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<tr>
<td></td>
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<td></td>
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<tr>
<td>Influence of incentive on</td>
</tr>
<tr>
<td>performance</td>
</tr>
<tr>
<td>Incentive to staff</td>
</tr>
<tr>
<td>SCOT, KFSH&amp;RC and MOH</td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Responsibilities</td>
</tr>
<tr>
<td>Donors and families</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Reports and evaluations</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td>Governments legislation</td>
</tr>
</tbody>
</table>
3.1.1 Administrative: Twelve documents were examined (Appendix 1). The need for the creation of MDAT was expressed in several documents:

“The concept of donor promotion needs to be changed to more proactive approach by directly getting involved in ICU in order to sort out all logistical problem related to organ donation.” Document no. 1, Administrative (Appendix 1)

Contractual issues were the subject of others. In 2006, a team started by two coordinators and one driver transferred from other departments. In 2007, more staff was recruited, including two physicians to meet the need for expansion:

“The MDAT has made big strides covering 40-50% of Riyadh region. With the success so far accomplished, it becomes logical to expand the team to be able to cover the other half of Riyadh ….request creation of new MSR line [job] for an extra coordinator” Document no. 8, Administrative (Appendix 1)

In the subsequent years, documents were implying requests for rewards and bonuses. The tone in some indicates frustration in the way the work of the MDAT is rewarded. This was attributed to the lack of understanding of the nature of the MDAT work by the administration. (Document nos. 4 to 11 in Incentives, Appendix 1).

“…The business leaves of …were not yet paid…Request for immediate assistance in paying these leaves”

Because the team had a dual reporting mechanism (SCOT and KFSH&RC), there was confusion leading to conflicts. This subsequently
eased off when an administrator from KFSH&RC was appointed

(Document no. 7, Administrative, Appendix 1)

3.1.2 Training and Development: Two coordinators with minimal medical background were sent to UK, Spain and USA for short training periods. Two physicians were then recruited. Early on 2007, an external expert spent six weeks with the team for evaluation and training. These training opportunities were based on the Western system in organ donation, which relies on the altruistic model and an agreed-upon code of conduct (see training in Appendix 1).

3.1.3 Logistics: Since the work of MDAT is in the field, mobility is an essential part of its function. Four documents examined were related to provision of means of transportation, mobile EEG machine and drugs and equipment (see logistics in Appendix 1).

3.1.4 Budget and Fund Raising: Base on 17 documents in early 2006, financing the operation of the team was through fund-raising and charity. However, salaries were paid by KFSH&RC and financial incentives to families of the deceased (12,000 USD) were paid by the government. The budget was inconsistent, with times when the lack of money caused sluggish performance. Several documents indicated fierce attempts to get a
monthly operational budget, which eventually succeeded; (Document 15, budgetary, Appendix 1).

In 2008, a monthly budget of around 12,000 USD was allocated to cover the operation of the team. Receipts were examined including bills for services such as EEG reading, blood work, etc. as well as administrative cost of funeral expenses and body transfers.

3.1.5 Incentives to ICU staff and MDAT Members: An institutional document (Document 1 in Incentives, Appendix 1) back in 2001 permitted incentives for health care workers inside and outside the institution upon having a successful procurement (around 250 USD each)

“Incentives will be paid based on productivity of participants…1,000 SAR for each participant per case.”

Throughout, there was no ethical hesitation to pay incentives for donor families or health care workers. The difficulty seems to be procedural bureaucracy.

In 2006 and 2007, revised documents dealt with the distribution of incentives to health care providers in the form of direct and indirect payment (conferences, scientific activities etc.). Late in 2007 and 2008, there were several documents requesting KFSH&RC to pay incentives to the MDAT members; with a tone of frustration that such well-deserved
incentives are not being met. Others were related to obtaining funds from individuals or institution through charity.

3.1.6 SCOT, KFSH&RC and Ministry of Health: Four main documents were examined in relation to the working relation between three parties involved with the creation of MDAT:

- SCOT, who is the official procurement agency.
- KFSH&RC, which houses the biggest transplant programs in the country and the initiator of MDAT.
- Council of health services chaired by the Minister of Health. This council is the highest health authority in the country.

Early in 2005, KFSH&RC presented the idea of MDAT as a concept to solve the organ shortage crisis. Evidence from a pilot project was presented. The council sent the proposal to SCOT. Though there was no official agreement, KFSH&RC continued piloting the project. KFSH&RC went back to the council in early 2006 with even better results. The council ordered SCOT to establish the team in collaboration with KFSH&RC. SCOT asked for the Ministry of Health Support (to which SCOT reported) but was not granted. KFSH&RC took the initiative of providing the needed support (manpower, financial support and logistics) through a series of memorandum of understanding and agreements between the Director of
SCOT and the CEO of KFSH&RC. Of particular interest is a document from SCOT sent to the council protesting a report sent by KFSH&RC about the outstanding result achieved in which SCOT complained about being under-recognized. It brought to the surface the tension between the two parties.

“We [SCOT] were expecting that we are the one who should present the report about the activities of MDAT since it is not only KFSH&RC who participates in MDAT activities but others as well” Document no. 4, SCOT, Appendix 1

This tension was expressed in a report by an international expert in the field:

“There was some general animosity between the two groups as the MDAT was being viewed as more aligned and ‘belong’ to KFSH&RC and not with SCOT.” Document no. 2, Reports, Appendix 1

Later in 2008, documents indicated a need to duplicate the project in other regions in the country.

3.1.7 Documents pertaining to donors and donors’ families: Copies of checks and money transfers were examined indicating the actual payment by the government of the amount of 12,000 USD to the families of the deceased. Illustrative examples were examined indicating the people involved in the process, the logistical sequence of donation and the outcome of the donation process. A document of an interview with a father of a donor who accepted financial incentives was examined. The father
justified his acceptance morally by indicating that money obtained will be used to support his poor family. In the coordinator’s words:

“He started looking for excuses that the money will be used to spend on the rest of the children and the mother since the family is poor…He mentioned something in passing about using the money for the charity” *Document no. 3, Donors, Appendix 1*

### 3.1.8 Reports and Evaluations:*

The first in-depth evaluation was made early in 2006 by an international expert. Subsequently, several reports were sent to the hospital authorities and the Council of Health Services to demonstrate the rise in donation rate and to ask for more support:

“It is worth mentioning that for the first time in the history of organ donation in the Kingdom, we were able to have 80 consented donors. As you know each donor could save 4 to 5 patients. As a result in 2008 a total of 300 organ failure patients were saved! Therefore we would request creation of more MSR lines [jobs]” *Document no. 4, Evaluation and Reports, Appendix 1*

A report of an international expert affirmed the success of MDAT and suggested its transferability:

“The concept of a mobile team to clinically facilitate donation has merit and alignment with SCOT is paramount to its future success. It’s a model which can be implemented in other areas in the Kingdom with some modification and the full support and guidance of SCOT” *Document no 2, Reports, Appendix 1*

### 3.1.9 Government Documents and Legislation:*

Organ donation and transplantation is permissible in KSA based on two scholarly documents; the first was produced by The High Ulama (Scholars) Council on August 1982 and the second is based on the Islamic Council Declaration on
February 1982. The Cabinet of Ministers (the highest executive body in the government) approved a reward for the families of a deceased donor amounting to 30,000 SAR (Saudi Riyals; equivalent to 8,000 USD) on December 1993 and increased to 50,000 SAR (12,000 USD) on October 2002.

Incentives for the coordinators and health care workers were approved by the Health Services Council as well as by SCOT and KFSH&RC between 2006 and 2009.

3.1.10 Summary: The document review gave an insight into the evolution of MDAT and a contextual background for the research. MDAT was created to meet the needs of the transplant programs. The administrative confusion caused by diverse interests of multiple stakeholders did not hinder the team’s success. The success was attributed to the structural changes and the judicious use of incentives for both families of deceased and health workers. There were neither institutional nor governmental objections to this approach nor an explicit ethical or moral objection from the side of families or the health workers. There was expression of frustration by MDAT for under-recognition. Western training did not influence their attitude and practice towards the use of incentives. Documents review provided a tool to shape the in-depth interview question (as shown in
3.2 In-depth Interview Results:

Table 8. Interviews’ themes and sub-themes are summarized below:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasons for increase in donation</td>
<td>Organizational changes</td>
</tr>
<tr>
<td></td>
<td>Incentives</td>
</tr>
<tr>
<td></td>
<td>awareness</td>
</tr>
<tr>
<td>The draw back of incentives</td>
<td>Absence of contradiction between donation and incentives</td>
</tr>
<tr>
<td></td>
<td>Concept of reward</td>
</tr>
<tr>
<td></td>
<td>Religious acceptance of incentives</td>
</tr>
<tr>
<td></td>
<td>Adequacy in amount</td>
</tr>
<tr>
<td></td>
<td>Logistical issue</td>
</tr>
<tr>
<td>Medical advantages</td>
<td>Quality of organs</td>
</tr>
<tr>
<td></td>
<td>Value of organs</td>
</tr>
<tr>
<td>Religious and cultural</td>
<td>Ethical concern with IBPS</td>
</tr>
<tr>
<td></td>
<td>Ethical obligation towards needy patients</td>
</tr>
<tr>
<td></td>
<td>Religious (Islamic) view carries a lot of weight in the acceptance of IBPS</td>
</tr>
<tr>
<td>Economic advantages</td>
<td>IBPS saves money</td>
</tr>
<tr>
<td></td>
<td>Comparison to transplant abroad</td>
</tr>
<tr>
<td>Transferability</td>
<td>Potentially in Middle East</td>
</tr>
<tr>
<td></td>
<td>May or may not be applicable in the West</td>
</tr>
<tr>
<td></td>
<td>Economic class and level of education can determine transferability</td>
</tr>
<tr>
<td>Degree of satisfaction</td>
<td>High degree of satisfaction</td>
</tr>
<tr>
<td></td>
<td>Moral and religious issues are of concern</td>
</tr>
<tr>
<td></td>
<td>Moral obligation to patients</td>
</tr>
<tr>
<td>Incentives for MDAT</td>
<td>inadequate</td>
</tr>
<tr>
<td></td>
<td>MDAT work undervalued</td>
</tr>
<tr>
<td>Influence of Western training</td>
<td>Affect structural side</td>
</tr>
<tr>
<td></td>
<td>No influence on the practice of IBPS</td>
</tr>
<tr>
<td>Other strategies to increase donation</td>
<td>Expand IBPS</td>
</tr>
<tr>
<td></td>
<td>Better administrative structure</td>
</tr>
<tr>
<td></td>
<td>More administrative support</td>
</tr>
<tr>
<td></td>
<td>More staff and resources</td>
</tr>
</tbody>
</table>
3.2.1 Reasons for the Increase in Donation. These were grouped into three sub-themes:

- Organizational
- Incentives
- Awareness

The organizational aspect was related to the structural changes in the operation of the team including availability of a flexible budget. Fieldwork was conducted with face-to-face relationships with the intensive care units’ personnel in a way that met their needs. This was very effective in the opinion of most participants.

“The system, [organization of the procurement} is the reason [for the increase]” -RS

“It is not one but number of reasons………good relationship with the ICU team in other hospitals and we were able to get closer to them and explain the goal of the whole subject” --TA

A very important aspect of such organizational change was the shift of organ donation burden from the ICU staff to that of MDAT members.

“Its [looking after donor] like a headache to the physicians, now, it is no longer that. The physician thinks, [to himself] ‘I will have a break from this bed [the donor], the moment the case is notified as brain dead, a complete medical team would come and take care of this issue’ ” –AB

The relationship created also led to more awareness of the subject of donation among ICU personnel resulting in more donor referrals:
“The main reason...is the increase awareness in the hospitals, the Intensivist in the ICU was not aware of this issue [organ donation] or how to notify it” -AB

Incentives were considered by all participants as the most important factor in such an increase. This includes financial incentives to the families of the deceased and to the medical personnel (ICU staff).

“If you are not paying, the people who are supposed to do the EEG, they would not make an effort, it would not be done at 9:00 at night; more likely it will be done the following day.” –RS

The weight of this factor was very heavy in the opinion of most participants with the assertion that if such strategy were absent the donation rate would drop remarkably.

“...[T]he incentives are on the top.......70% [depends on] incentives and 30% organization” --AA

“The system [had an effect on organ procurement] and if there were no incentives even if there was a system, it will not work” -RS

One of the participants emphasized the importance of funeral costs and the transfer of the body to the country of origin for the Non-Saudis as a strong motivation for the acceptance of organ procurement.

3.2.2 The Drawback of Incentives. The sub-theme brought up by the participants was the absence of contradiction between donation and incentives. Both were viewed as complimentary to each other. The concept
of “reward after the fact” rather than “monetary price” for the organ was the concept brought by several participants.

“. I think it [financial incentive] is good, this is a reward. It is a show of appreciation” - TA

The majority of opinions were in agreement with the moral and ethical values.

“I understand it [IBPS] as saving lives ……I don’t mind how much you pay in order to save his life[patient]. I think it is morally correct” - TA

Three participants expressed some concerns about the religious acceptance of incentives and wished there was an explicit religious declaration supporting incentives for organ procurement:

“…. [N]ot convinced from inside [about incentives], sometimes, I am convinced 100 % that he [deceased] should be paid; because of the number of people in the waiting list…………. getting into buy and sell [commodifying] and what religion says about it, but I have no solid decision. I wish we have a clear religious declaration.” – MA

The drawbacks were the inadequate amount and the explicit expression of the value of organs for patients, which justify an even bigger amount of monetary compensation.

“It [increasing incentives] will triple or more [the number of donors], because …… [we] motivate them.” – AN

Problems related to who should get the money was a rare occurrence:

“Rarely we see dispute among family members about who get the money and how money is distributed.” – BB
3.2.3 Medical Advantage: Invariably all agreed on the medical advantages of using the incentive in order to save lives by increasing the numbers and accelerating the donation process leading to a better quality organ and subsequently, a better organ transplantation outcome.

“The money makes the process [procurement of organs] quicker; so you can get better organs.” -BB

3.2.4 Religious and Cultural Issues: In general, the practice of IBPS among MDAT members was not influenced by ethical concerns. Some saw IBPS as a means to fulfill their ethical obligation to patients who are in need of organs besides benefiting the donor families. Though some participants did have some moral and ethical concerns; the majority regards incentives to be morally and ethically acceptable. Invariably the concern, if voiced, was more moral and religious in nature (Islamic).

“Primarily I am worried of getting into Haram and Halal [permissible or non-permissible from the religious point of view] and secondarily the issue of dealing with donor as if you are dealing with goods.” –MA

Accepting incentives did not seem to negate or downsize the deed brought about by allowing organ procurement from the deceased. One participant looks at these two aspects as complimentary to one another.

“...God ask to say in prayers “Oh God, give us all good things in the World and the hereafter”, so God will give you better for worldly affairs and He said that first, so the person who would do good deed for Allah’s [God] sake, does a big thing, and save the life of a human being, before you thank him in our religion, he should be thanked in the world [incentives] and that is what our religion says...” –AA
3.2.5 Economic Advantages: Comparing the cost spent on organ donation to that of the cost of medical care or sending patients abroad, it was an invariable opinion of the group that IBPS has big money saving economic advantages and therefore more incentives need to be given to all parties involved.

“… [P]atient on hemodialysis cost a lot. If we transplant them we will save a lot of money some of that money, even a fraction, can make a big difference in organ donation when we use it as incentives.” -AA

3.2.6 Transferability: Most participants expressed strong opinion in terms of transferability of IBPS to other countries. A sub-theme linked IBPS success to the social and economic situation of different countries so that the poor and less educated will have more success with the system.

“It [IBPS] is likely that it will work better in poor and less educated societies but it should not contradict donation system. It can be complimentary.”

-RS

The opinion on the transferability to Western countries was diverse. The majority were in favor of predicting success of IBPS, even in the wealthy Western countries with high level of education.

“It will depend on economic situation. I presume that donation is the main motivation and the financial incentive is a factor that aids donation, when a person does not need it [money] he can decline.”

-TA
3.2.7 Degree of Satisfaction: All participants were satisfied with the positive impact of incentives on the procurement rates. There was, however, some concern about the ethical and moral aspects expressed in religious terms but these concerns were not strongly expressed:

“Definitely I am doing a good job, because I am helping both sides the family of the donor and the patients.”

- BB

3.2.8 Incentives for MDAT: All participants expressed their desire to have incentives based on the performance of the team; that is a reward per case. There was a feeling of injustice in the exclusion of MDAT members from benefits of incentives.

“The Mobile Team’s basic work is very hard…….their rights are devoured, they are the people who get the least.” -- AA

3.2.9 Influence of Western Training: Most participants were exposed to the Western medical training in one way or the other. It was clear that this had no effect on their attitude towards IBPS.

“My work and training in the West does not influence my attitude towards incentive. I truly believe that this will work in the West.”

-RS

3.2.10 Other Strategies: All participants agreed that more incentives to the team, families and ICU staff will enhance the performance and bring more donors.
“The incentives for the team, is as important to you as those to family”—TA

The need for more staffing and better management was expressed by some as important factors in the enhancement of the MDAT work.

3.2.11 Summary: Though structural changes had an influence on increasing organ procurement, it was the opinion of all participants that the financial incentives were the main reason for this increase. Moral and ethical issues were not a deterrent to application of IBPS. On the contrary, the degree of satisfaction with the IBPS was rated very high by some and was considered as a moral obligation to the needy patients by all of them. There were concerns in regard to the ambiguous religious stance on the subject by a few participants. The economic and medical advantages of IBPS were apparent to all of them. Applicability of IBPS to the rest of KSA was considered feasible as well as to neighboring Middle East countries. Some doubted its applicability to Western societies because of culture, economics and literacy. All agreed that there is a big room for getting even better results with a more aggressive application of IBPS.
4. Discussion

4.1 Key Findings and their Implications: The key findings within the stated research question, aims, objectives and their implication, are summarized as follows:

4.1.1 Increase in procurement rate: This work unequivocally showed a three-fold increase in donation rate in Riyadh, KSA from 2006 to 2009. This increase was confined to Riyadh only, as it compared to other regions in KSA. The magnitude of this change can be appreciated if we compare it to other donation initiatives such as Organ Donation Breakthrough Collaborative in the USA, which adopted the best practices in the process of organ recovery and allocation and led to a marginal increase in conversion rate from 50% to 60% (Childress and Liverman, 2006). The Massachusetts organ donation initiative increased the conversion rate from 44.2% before intervention to that of 59.5% at its peak to drop as low 37.8% after two years since the commencement of the initiative with actual number of donors 73,103 and 59 respectively (Koh et al., 2007)

4.1.2 The Reasons of the Increase in Procurement Rate: Though structural change in the procurement process such as aggressive fieldwork by MDAT contributed to this increase, it was the opinion of all practicing MDAT members that incentive played a major role. The majority believed that
even with the best practice, the increase would be marginal, if not accompanied by the use of incentives. This was supported by document review, which did show sluggish activities during the time of financial difficulties. Though contribution of each of these two factors cannot be accurately measured without comparative studies, this work presents convincing evidence in favor of incentives.

4.1.3 **Ethical, Moral and Cultural Issues:** The findings of document review confirmed the State (KSA) and institutional ethical acceptance of the use of incentive. The interview results also confirmed moral acceptance by most participants. The practice was viewed by some as a tool to fulfill the moral obligation to patients, who are in need of organs and by others as a pragmatic exchange of benefits. One of the participant considered the two complimentary; the first seeking *a deed for second life* and the second getting a benefit in the *current life*. This idea contrasts with Western opinion, which views the two concepts incongruous (Delmonico et al., 2002). Some even expressed fear that the introduction of incentive can deter people who otherwise would donate (Prottas, 1992; Byrne and Thompson, 2001).

4.1.4 **Transferability:** It was the opinion of all participants that IBPS can be transferred to other regions in the Kingdom. Considering similarities of
Table 9. Institute of Medicine Objection on IBPS:
- Lack of empirical data to support IBPS.
- Obtaining data is blocked by the reluctance in conducting pilot studies in IBPS either because of ethical concern or the fear of setting an irreversible societal motion which can undermine the current ADS.
- Insistence on the reliance on structural changes in the current system to bring about a resolution to the organ shortage crisis such as quality improvements and collaborative initiatives.
- Debate on who should provide the burden of proof, opponents or proponents of IBPS.
- Ethical constraint: although most agree that these should not be the decisive factor in adopting IBPS.

Therefore, it is plausible that it will be a long way before IBPS is applied in Western countries; though some of the participants believed in its applicability in the Western systems. However, reflecting on the experience of Wisconsin Staten with Cody’s Law on compensation for living donation, it is likely that IBPS will need a very complicated process for approval (Wieckert et al., 2009). Work like this once applied on large scale might fill some of the knowledge gap created by the lack of empirical data on the subject.
4.1.5 IBPS Ethical Framework: One of the important key findings of this study is the IBPS deviation from the current donation procurement system. The two contrasting procurement systems are the “Routine Salvage Model” and the “Donation Model”. The ethical underpinning of the first model is consequential social utilitarianism focusing on the benefit of the society and that of the second is a combination of virtue and deontological ethics focusing on the individual autonomy and virtue (Veatch, 2000). The ideal model should have a maximizing power to obtain all potential organs while maintaining moral value. This is the dilemma of organ shortage (Abouna, 2008).

We argue for IBPS to position itself in between; trying to meet the obligations of autonomy, justice and utility. It pragmatically creates a win-win situation for the recipients and the family of the deceased; at least from economical perspective. Though in general, the practice was morally and ethically acceptable, some of the respondents expressed religious concerns and hoped for an explicit religious declaration. This is understandable, considering the non-secular nature of Saudi society. Currently, efforts to address organ shortage are within the constraining boundaries of the altruistic donation ethical framework (Arnold, 2002). This is associated with limited success (refer to section 4.4.2). We argue for
modification of this ethical framework to accommodate IBPS, which proved to be effective based on the Riyadh experience.

4.1.6 Summary: This study answered the research question by demonstrating an increase in procurement rate, feasibility of IBPS and potential transferability. A rival interpretation attributes this increase to the structural change in the organ procurement approach. Though this might hold partially true, interviews unequivocally put incentives as the main reason for this increase. Contrary to what some authors predicted, the use of incentives did not cause a paradoxical decrease in the altruistic donation rate (Prottas, 1992; Arnold et al., 2002; Byrne and Thompson, 2001). It was the opinion of participant that altruism and incentive could be complimentary rather than contradictory.

The document review gave an insight into the evolutionary process of MDAT and identified its barriers, which is one of the study’s aims and objectives. Insufficient financial support, bureaucratic processes and administrative confusion were the main challenges for the team. The study aimed at examining the religious, cultural and social issues related to IBPS. Those and the ethical and moral issues did not seem to affect the practice. This was applicable to the research setting. Another objective was to give a recommendation to the transplant community and health authority in KSA
regarding transferability and areas of further research. The outcome of this research cannot predict applicability to other settings, though potentially it is conceivable that IBPS can be applied in other KSA regions and perhaps in other Middle Eastern countries. Further research need to be conducted to confirm the result of this study.

4.2 Strength and limitation

4.2.1 Originality: The strength of this work lies in its originality. There is a plethora of literature (see introductory section) on the subject of incentives in organ procurement; however this the first time the subject is taken into a practical real life context rather than theoretical rhetoric debate. This should encourage pilot projects to test its applicability to other settings.

4.2.2 Setting: This work was done in the setting of organ donation system in Riyadh, KSA. Organ donation is largely influenced by the health care system, social and cultural context. Qualitative research can take account of these aspects. The setting was chosen because there was no alternative option. Though IBPS is permitted in KSA, it is widely practice in Riyadh only (population of 5 million). The strength of this setting is in its resemblance to other regions in the KSA, which may predict transferability. This may not be the case in Western settings with different IBPS
legislations, social and political fabric (Wieckert et al., 2009). Applicability within the Western social-political systems is a major limitation.

4.2.3 Research Design and Methodology: The design and methodology chosen was qualitative case study based on document review and in-depth interview. Quantitative research was an alternative; however it would have been deficient in addressing a socially constructed phenomenon such as organ donation. This is an area loaded with perspectivism (Schicktanz, 2008), which can be explored deeply through qualitative methodology. The sample chosen were members of MDAT who actually practice IBPS. Being in the field strengthens this sample while the number and lack of diversity may be a limitation. The homogenous nature of the sample may be considered both ways; consistency and congruence were strengths and the lack of deviance, which can enrich the case study, might be a limitation (Yin, 2009). An alternative sample would have been family members of the deceased since the issue of incentives is more relevant to them. It would have enriched the case study by probing issues, which can determine their acceptance of organ procurement. However, this would have been an emotionally laden encounter that may not be ethically appropriate andlogistically difficult. A participant observational methodology (Schwandt, 2007) during the actual solicitation of consent might have been the best
way to answer the research question, however because of logistical difficulties, ethical issues and the potential involvement of the researcher in a highly emotionally laden situation, this was not pursued. The closest approach to get an insight into IBPS was the interview of MDAT members who were the main source of information on IBPS. A focus group (Kruger, 2000) was not used in this research. As a stand-alone, it might not be enough to address the research question though it was proposed by the researcher as a confirmatory tool; for logistical reasons, it was replaced by participant follow-up inquiry. The size of the sample and its composition may skew the result towards accepting IBPS. Positionality may have played a role in the data collection and analysis process. The positionality of the researcher strengthens the research by his familiarity with the persons, scene and the social and religious backgrounds. It might however create a bias towards IBPS since it had a beneficial influence on the researcher’s transplant program.

4.2.4 Rigor: General criteria of rigorous analysis of qualitative data as outlined by Green and Thorogood (2004, p.191) include: transparency, validity, reliability, comparability and reflexivity.

*Transparency:* In this work a clear account of the methodology, researcher positionality and his solo involvement was outlined.
Validity: Data coming from interview are based on constructionist tradition of qualitative research, which can make validity of interpretation of data problematic. Green and Thorogood (2004) suggested several check techniques such as looking for disconfirming evidence (deviant case), simple count, contextual support to the findings and member validation. No deviant cases were found and simple count was not useful because of the small number of participants. The context of the research was elaborately described and gave support to the findings. Member validation was also supportive.

Reliability: This is the repeatability of the interpretation when coding and analysis of data performed by multiple researchers, which was not done. Good practice in handling data was attempted. Examples of raw data and their interpretation are shown in the appendices.

Reflexivity: The researcher is familiar with organ donation and transplantation, the IBPS and MDAT members. The researcher tried to be objective during documents collection and analysis. All documents available were examined, classified and interpreted based on their contents. Explanations and assurances were given to the participants in order to get what reflects their beliefs, rather than what the researcher wants.
Despite the above-mentioned, high degree rigor in such a research is unattainable and need to be accepted as a feature of qualitative research.

4.2.5 Lesson Learned: The qualitative approach in this study is not common in an area dominated by a biomedical paradigm. The acceptance of organ procurement/donation, by all parties involved, is based on perspectivism as shaped by social, cultural and religious determinants. This makes qualitative approach more appropriate.

Document collection was a tedious and time-consuming process, however it brought the pieces of the puzzle together to portray a picture and tell the story of MDAT in Riyadh, KSA. This real-life story illustrates the difficulties facing organ procurement teams and how these problems were solved. Using financial incentives is a unique experience in this setting. Participants interview gave in-depth understanding of their practice with IBPS. Other methods of data collection may be considered in future research. Interviewing family members may get us closer to the subject than MDAT members. Participatory research (Schwandt, 2007) may get us even closer; by being part of the scene during the solicitation of consent from the relatives of deceased. Obviously, logistical and ethical issues need to be addressed. The sample was inclusive since IBPS is not practiced anywhere else. Future research may have the opportunity of including more
participants; if IBPS is applied in another setting. It is likely that this will be the case; at least in KSA and perhaps in other neighboring countries. Triangulation increased the validity and reliability of the study. This was attempted by using two data collection tools. Focus group, an important data collection tool was planned but was not executed due to logistical reasons. It was replaced by confirmatory inquiry of the participant. In a single-handed research like this, one needs to be realistic about the time and effort devoted to data collection and analysis. Though multiple data collection increases validity and reliability; it can produce unmanageable amount of data. This was the experience of the researcher.

4.3 Health Economics and Public Health Relevance:

Acheson report (Last, 2001) defines public health as “The science and art of preventing disease, prolonging life and promoting health through organized effort of the society”. Since biomedical structural changes within the current system failed to alleviate organ shortage, we call for an organized holistic effort by the society to adopt IBPS to mitigate organ shortage. The problem of organ shortage affects health care system in most countries. This is exemplified by considering the case of renal dialysis. Government and societies are obliged to support dialysis and
therefore the cost of dialysis can be used as a benchmark in comparison to transplantation. The annual cost of dialysis at KFSH&RC is between 50,000 to 80,000 USD annually. It was reduced by 90% with renal transplant after the 3rd year; a finding similar to that of Kalo (2003). The table below shows a cost analysis of dialysis versus renal transplant at KFSH&RC:

**Table 10.** Cost of renal transplant vs. dialysis at KFSH&RC, Riyadh, Saudi Arabia.

<table>
<thead>
<tr>
<th>Annual cost</th>
<th>Renal transplant</th>
<th>Dialysis (Annual average)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First year</td>
<td>133,291 USD</td>
<td>79,756 USD</td>
</tr>
<tr>
<td>Second year</td>
<td>14,233 USD</td>
<td></td>
</tr>
<tr>
<td><strong>Cumulative (2 yrs)</strong></td>
<td><strong>147,524 USD</strong></td>
<td><strong>159,512 USD</strong></td>
</tr>
<tr>
<td>Third year</td>
<td>5,536 USD</td>
<td></td>
</tr>
<tr>
<td>Fourth year</td>
<td>4,402 USD</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>157,462 USD</strong></td>
<td><strong>319,024 USD</strong></td>
</tr>
</tbody>
</table>

USD: US dollars

health economics, health care priority setting, and in turn, affect public health (Mitton and Donaldson, 2004; Mitton, 2004). The cost-effectiveness of cadaveric procurement has been well-established (Machnicki et al., 2006; Mendeloff, 2004; Schnitzler et al., 2005).

4.4 **Recommendations:** In addressing organ shortage the following steps are recommended:

4.4.1 **Awareness of the Benefits of Transplantation and Crisis of Organ Shortage:** In order to create an impetus for organ transplantation,
awareness of its benefits must be invoked among the public and health care policy maker. Limitation of transplantation namely organ shortage must be put in a clear perspective to highlight the failure of the current altruistic system.

4.4.2 Structural Change in the Logistics of Organ Donation: What follows after being aware is a structural change in the logistics of donation to make it the most efficient. This should be done through a fieldwork identifying the problems and finding solutions applicable on the ground. This obviously will differ from one setting to the other.

4.4.3 Towards Piloting IBPS: The failure of the current donation system calls for alternatives. The ethical and moral fear of applying IBPS should be overcome. Though it seems feasible to apply this system at a large scale in some settings such as KSA, other countries and societies may not appear ready. Pilot projects on a small scale is the first step to explore the system in real life to prepare for a wider applicability, if found suitable.

4.4.4 Future Research: Further research is needed. The limiting step in such perusal will be the acceptance of a pilot project of IBPS in Western countries. Without an actual real life experience with IBPS, no one can be certain about its impact on organ procurement. The researcher believes that surveys and theoretical arguments on the subject can be potentially
inaccurate and even misleading. The failure of altruistic donation system with its disastrous impact on organ transplantation and death on waiting lists should produce a much louder ethical cry than that produced by the call to use financial incentive to increase organ donation as elegantly expressed by Godlee (2008).

5. Conclusion

In conclusion, this qualitative study contributed to the vigorous quest of solving the crisis of organ shortage— an important public health problem— by arguing for financial incentives. It demonstrated the feasibility of using financial incentive as a tool to increase organ procurement through a real life case study in Riyadh, KSA. The fear of untoward social, cultural and ethical percussions of such practice seems to be unwarranted, at least in this setting. This should encourage others to apply it in their own settings. Our current knowledge of the subject is based on theoretical assumptions, public and professional surveys. The lack of empirical real life studies created a gap in our knowledge. This study contributes to the filling of this gap.
6. References


# Appendices

## Appendix 1. List of documents examined.

<table>
<thead>
<tr>
<th>No.</th>
<th>Subject:</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Justification letter to create MDAT</td>
<td>17.12.05</td>
</tr>
<tr>
<td>2.</td>
<td>MSR line for a physician and 2 coordinators</td>
<td>21.12.05</td>
</tr>
<tr>
<td>3.</td>
<td>Creation of joint office and the support of organ transplant programs of KFSH7RC to that office (3 documents)</td>
<td>01.01.06</td>
</tr>
<tr>
<td>4.</td>
<td>Change in reporting mechanism of MDAT</td>
<td>17.01.06</td>
</tr>
<tr>
<td>5.</td>
<td>Hiring a physician as a medical coordinator</td>
<td>17.03.06</td>
</tr>
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<td>6.</td>
<td>Approval of the above</td>
<td>08.05.06</td>
</tr>
<tr>
<td>7.</td>
<td>Assignment of director of team with job description</td>
<td>14.01.07</td>
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<tr>
<td>8.</td>
<td>Request to create a line for clinical coordinator</td>
<td>23.10.07</td>
</tr>
<tr>
<td>9.</td>
<td>Hiring of coordinator</td>
<td>01.03.08</td>
</tr>
<tr>
<td>10.</td>
<td>Assignment of team leader within MDAT</td>
<td>24.03.08</td>
</tr>
<tr>
<td>11.</td>
<td>Authority for business leaves</td>
<td>09.06.08</td>
</tr>
<tr>
<td>12.</td>
<td>New job for a coordinator</td>
<td>07.10.09</td>
</tr>
<tr>
<td></td>
<td><strong>2. Training</strong></td>
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</tr>
<tr>
<td>1.</td>
<td>Request to link MDAT training to international organization</td>
<td>22.03.06</td>
</tr>
<tr>
<td>2.</td>
<td>Approval of 2 month in house training by international expert</td>
<td>01.10.06</td>
</tr>
<tr>
<td>3.</td>
<td>Concise course done by KFSH&amp;RC training and development</td>
<td>24.03.07</td>
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<tr>
<td>4.</td>
<td>Training on EEG machine</td>
<td>04.04.07</td>
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<tr>
<td></td>
<td><strong>3. Logistics</strong></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Request of SCOT to provide cars</td>
<td>04.01.06</td>
</tr>
<tr>
<td>2.</td>
<td>Notification of car purchase</td>
<td>04.03.06</td>
</tr>
<tr>
<td>3.</td>
<td>Request for Donor kit (medication and fluid to support donors)</td>
<td>20.05.06</td>
</tr>
<tr>
<td>4.</td>
<td>Request for mobile EEG machine</td>
<td>17.05.07</td>
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<td>5.</td>
<td>Request for vehicle</td>
<td>20.11.07</td>
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<td></td>
<td><strong>4. Budget and Fund Raising</strong></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Request for petty cash with list of expected expenditures</td>
<td>20.02.06</td>
</tr>
<tr>
<td>2.</td>
<td>Rejection of petty cash request by finance</td>
<td>26.02.06</td>
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<tr>
<td>3.</td>
<td>Purchase of EEG machine</td>
<td>22.02.06</td>
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<tr>
<td>4.</td>
<td>Fund for incentive of health care providers given by health outreach program of KFSH&amp;RC</td>
<td>19.03.06</td>
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<td>5.</td>
<td>Request for petty cash and details of installments</td>
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<td>6.</td>
<td>Creation of a donation fund bank account</td>
<td>01.05.06</td>
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<tr>
<td>7.</td>
<td>Logistics of deposition in the above</td>
<td>03.05.06</td>
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<td>8.</td>
<td>Request for sponsoring education activity by a pharmaceutical firm.</td>
<td>13.05.06</td>
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<td>9.</td>
<td>Donation by a commercial medical firm</td>
<td>17.05.06</td>
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<tr>
<td>10.</td>
<td>Fund transfer from health outreach program</td>
<td>26.09.06</td>
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<td></td>
<td>Request for 2007 incentives budget (1.2 million SAR)</td>
<td>24.12.06</td>
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<tr>
<td>12.</td>
<td>Insufficient fund</td>
<td>23.04.08</td>
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<tr>
<td>13.</td>
<td>Request for fund from health outreach</td>
<td>30.04.08</td>
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<tr>
<td>14.</td>
<td>Same as above</td>
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<tr>
<td>15.</td>
<td>Establishment of petty cash fund from hospital revenue</td>
<td>01.07.08</td>
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<td>16.</td>
<td>Request for health outreach to support MDAT</td>
<td>13.01.09</td>
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<tr>
<td>17.</td>
<td>Request for Contingency plan for MDAT funding</td>
<td>07.03.09</td>
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### 5. Incentives for MDAT and health workers

<table>
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<tr>
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<tbody>
<tr>
<td>1.</td>
<td>Institutional approval of incentives for health care worker working with donors (from outside institution.)</td>
</tr>
<tr>
<td>2.</td>
<td>Organization steps in payment of incentives for ICU staff</td>
</tr>
<tr>
<td>3.</td>
<td>Request to issue a check of 2000 for an Intensivist</td>
</tr>
<tr>
<td>4.</td>
<td>Request for performance bonus</td>
</tr>
<tr>
<td>5.</td>
<td>Expedite incentives for MDAT</td>
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<tr>
<td>6.</td>
<td>Payment for overtime and on-call for MDAT</td>
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<td>7.</td>
<td>Business leave</td>
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<td>8.</td>
<td>Unpaid business leaves for MDAT</td>
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<td>9.</td>
<td>Transportation allowance for MDAT</td>
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<tr>
<td>10.</td>
<td>Promotions and incentive for MDAT</td>
</tr>
<tr>
<td>11.</td>
<td>Rejection of a promotion</td>
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</tbody>
</table>

### 6. SCOT, MOH and KFSH&RC

<table>
<thead>
<tr>
<th></th>
<th>Date</th>
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<tbody>
<tr>
<td>1.</td>
<td>Memo of understanding between SCOT and KFSH&amp;RC. Payment of 15 000/month to cover SCOT coordinator overtime expenses</td>
</tr>
<tr>
<td>2.</td>
<td>MOH decision to support ICU effort in organ donation and report of KFS&amp;RC on pilot project of MDAT</td>
</tr>
<tr>
<td>3.</td>
<td>Decision by MOH to support Riyadh team (MDAT)</td>
</tr>
<tr>
<td>4.</td>
<td>Letter from SCOT to Health Council Re-Report</td>
</tr>
</tbody>
</table>

### 7. Donor and Donor Families

<table>
<thead>
<tr>
<th></th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Inquiry about address of the family of a donor in order to send him check after donation</td>
</tr>
<tr>
<td>2.</td>
<td>List of donor and families to be given incentives presented by MDAT to SCOT</td>
</tr>
<tr>
<td>3.</td>
<td>Interview of a donor family</td>
</tr>
</tbody>
</table>

### 8. Governmental documents

<table>
<thead>
<tr>
<th></th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Declaration of Ulama on organ transplantation</td>
</tr>
<tr>
<td>2.</td>
<td>Declaration of Islamic council on brain death</td>
</tr>
<tr>
<td>3.</td>
<td>Decision of Minister Cabinet on incentives for donor families</td>
</tr>
<tr>
<td>4.</td>
<td>Decision of Minister Cabinet on increasing the amount of incentives</td>
</tr>
</tbody>
</table>

### 9. Reports and evaluations

<table>
<thead>
<tr>
<th></th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>First report from February till September 2006</td>
</tr>
</tbody>
</table>
2. Report on MDAT by international expert 27.02.06
3. Second report up till November 07 25.04.07
4. Report on achievement of October 2008 05.01.09
5. Third report till March 09 21.03.09

Total number of documents examined 65 documents

**Appendix 2. Example of in-depth interview.**

<table>
<thead>
<tr>
<th>No.</th>
<th>Transcript</th>
<th>Paraphrase</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>MS:</strong> How many years have you worked with the team?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td><strong>AB:</strong> About 4 years.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td><strong>MS:</strong> There was an increase in the number of cases? What do you think is the reason as to why the number has increased from the past?</td>
<td>ICU staff awareness leads to increase in donation</td>
<td>The number of donor has increased.</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td><strong>AB:</strong> The main reason and most importantly, is the increase in awareness in the hospitals, the Intensivist in the ICU was not aware of this issue [organ donation] or how to notify it. And till now, there are still some physicians who are not aware about donation and transplantation in the Kingdom. We have relieved a big load from the Intensivist or the staff in terms of diagnosis, maintenance, equipment, or even blood collection, they now are more relaxed in this area, it is now reversed, before, the center [SCOT] once informed about the case, there will be trouble: the call, blood collection, change of medication, its like a headache to the physicians, now, it is no longer that. The physician thinks, [to himself] “I will have a break from this bed [the donor], the moment the case is notified as brain dead, a complete medical team would come and take care of this issue”. The physician even has no administrative responsibility because the Team for SCOT [MDAT work under the umbrella of SCOT] will handle everything; I think this is the</td>
<td>SCOT and ICU consider organ donation a burden.</td>
<td>Awareness leads to increase in donation Organ donation logistics is considered a big load.</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
<td>MDAT took over the logistics of donation.</td>
</tr>
</tbody>
</table>
| Role of incentives | Community awareness.  
Religious influence on donation |
|-------------------|-----------------------------|

| Incentives are crucial to donation.  
Reluctance to mention incentives to family.  
Variation on the effect of incentives.  
Persuasion by incentives and negotiation? coercion  
Donation is considered as financial transaction by family.  
Majority change their mind with incentives (in 40 to |
|-------------------|-----------------------------|

| MS: Is there any other reason?  
AB: The community’s awareness, people have begun to realize the importance of organ donor. Some fatwa (religious declaration) also supported us, and programs [T.V] by Sheikh Salman Al Auda [famous religious scholar]. We wish that this would be repeated.  
MS: Let’s talk about in particularly, incentive, financial or otherwise, for the family of the deceased or the ICU team, in your opinion, does this have an effect?  
AB: Of course, it has a big role, let’s start for example, for the family, I realize that financial incentives have doubled, but there is the issue of how to communicate this to the family [tell them about incentives], and I noticed to some, that incentives makes a different, if we say, [effective in ] 70% for Saudi and non-Saudis 95%.  
MS: when you say, it makes a difference to them, do you mean that they refused then when they hear about the incentive, they would change their mind if there were incentives?  
AB: Yes, they could change their mind, [not only that but] there are some people, who would negotiate. No …..SR 50,000, [not enough] organ worth more than that [they would argue]  
MS: how many of the Saudi who |
<table>
<thead>
<tr>
<th></th>
<th>will go for the incentives</th>
<th>90% of refusal)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>AB: For Saudis about 30% for</td>
<td>Issue of incentives is embarrassing to some.</td>
</tr>
<tr>
<td>2</td>
<td>the time being.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>MS: Are there people who refused</td>
<td>Embarrassment in accepting incentives</td>
</tr>
<tr>
<td>4</td>
<td>first then would change their mind</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>after hearing the incentives and</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>would later agree?</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>AB: Some people during the</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>interview are embarrassed, then</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>after the consent, they come back to ask. I heard of the reward, I want my reward.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>MS: What is the percentage of</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Saudis who at first would refuse</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>then you tell them there is a reward then they would agree.</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>AB: About 40-50%.</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>MS: Non-Saudis?</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>AB: 90% of them</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>MS: So incentives have a big role to get the family’s approval?</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>AB: Yes</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>MS: Let’s talk about the family, what are the problems that is associated with giving incentives to the family? From your experience? Problems from the relatives, from logistics point of view or do things go smoothly?</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>AB: Sometimes, there are problems related to the delay in issuing the cheques or in relation to entitlement of who gets the money, I am not sure.</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Incentive can create problems afterwards.</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Racial and socio-economical difference in accepting incentives.</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Procedural problems related to incentives including family dispute.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3. Example of thematic analysis:

<table>
<thead>
<tr>
<th>Q1/theme</th>
<th>Reasons for increase in organ donation</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA.1</td>
<td>Incentives for families</td>
</tr>
<tr>
<td></td>
<td>Communication with ICU staff through field work.</td>
</tr>
<tr>
<td></td>
<td>Incentives to the ICU staff</td>
</tr>
<tr>
<td>RS.2</td>
<td>Money to the team and money to the relatives.</td>
</tr>
<tr>
<td></td>
<td>Organization supported by budget.</td>
</tr>
<tr>
<td>AB.3</td>
<td>Awareness among ICU staff.</td>
</tr>
<tr>
<td></td>
<td>Shifting the burden of donation logistics from them to MDAT.</td>
</tr>
<tr>
<td></td>
<td>Incentives for families.</td>
</tr>
<tr>
<td></td>
<td>Psychological pressure</td>
</tr>
<tr>
<td>MA.4</td>
<td>Monetary incentives for the families.</td>
</tr>
<tr>
<td></td>
<td>Availability of cash fund to support the operation of the team.</td>
</tr>
<tr>
<td>AAB.5</td>
<td>Awareness among all parties involved</td>
</tr>
<tr>
<td></td>
<td>Financial incentives.</td>
</tr>
<tr>
<td></td>
<td>Structural changes in the approach to organ donation</td>
</tr>
<tr>
<td>BB.6</td>
<td>Help in funeral arrangements such as transfer of the body to country of origin.</td>
</tr>
<tr>
<td></td>
<td>Financial incentives to families.</td>
</tr>
<tr>
<td></td>
<td>Organization of organ donation by MDAT</td>
</tr>
<tr>
<td>TA.7</td>
<td>Good working relationship with ICU staff.</td>
</tr>
<tr>
<td></td>
<td>Incentives to the families and ICU staff</td>
</tr>
<tr>
<td></td>
<td>Transfer of the body to country of origin.</td>
</tr>
<tr>
<td>AN.8</td>
<td>Organization.</td>
</tr>
<tr>
<td></td>
<td>Good relation with SCOT</td>
</tr>
<tr>
<td>FS.9</td>
<td>Aggressive on site approach to logistics of donation.</td>
</tr>
<tr>
<td></td>
<td>Meeting the needs for all parties involved.</td>
</tr>
</tbody>
</table>

Sub-themes

- Looking after brain death is a burden to ICU staff
- They have the right to get compensation.
- Incentive for families has the greatest impact on donation.
- Other factors will not work without incentives to families
- Money gives flexibility in the operation of the team.
- Dynamic needs of the team are met by prompt availability of money.
- Organ donation is considered a burden on the ICU staff.
- MDAT takes over the role of the ICU team.
- Elimination of incentives to ICU teams will definitely cause a drop in the donation rate.
Q2/theme  Negative side of incentives or the drawbacks

AA.1  Not enough
No contradiction between altruism and incentives.
Win-win situation.

RS.2  Morally accepted.
Family chooses the motivation.
Win-win situation

AB.3  Logistic.
May be religiously not acceptable
No consensus
Moral concern, organ trade
Reward rather than financial compensation.
The “State” labeled on incentives

MA.4  Moral concern, organ trade.
Confusion about religious aspects

AAB.5  Logistics
Concept of reward

BB.6  Morally acceptable.
Logistics.
Win-win situation

TA.7  Win-win situation.
Concept of reward.

AN.8  Logistics

FS.9  No other alternative.
Win-win situation

Sub-themes
• Donation is considered good deed even if incentives are given.
  Economic advantage to the family
• Who gets it?
• Delay in releasing the money.
• State’s reward rather than financial compensation
• Concern about treating bodies as commodity.
• Incentives not considered as an insult by the family.
• More comfortable if there’s religious declaration.
• More comfortable by the concept of reward by the State.
• More comfortable if offer of incentive after acceptance of donation.
• Incentives are act of necessity
Appendix 4. Proposal.

**Title:** Donor Organ Shortage Crisis: A Case Study Review of an Economic-Incentive System.

**Introduction and Background:** End stage organ failure is a major health problem leading to substantial social and economic losses. Since the 1950’s, organ transplantation made giant strides to become the standard of care with remarkable improvement in survival and quality of life for these patients (Morris, 2004). The number of patients on the waiting list as a consequence of the gross disparity between demand and supply resulting in organ shortage has become an important public health problem. The crisis of organ shortage is evident in that less than 10% of patients on the waiting lists got transplanted resulting in mortality of at least 5-10% while waiting (Matesanz and Rudge, 2005). In most countries, the current organ supply system depends on altruistic non-coercive donation. This model of volunteerism has been deficient in meeting an accelerated demand, a demand which is undermining the success of organ transplantation. The desperate demand for organs and the need to combat organ trafficking, transplant tourism and human exploitation has resulted in the search of effective alternatives by many interested parties. One of these alternatives is the use of financial incentives to increase the rate of donation. The debate continues about the feasibility of such an alternative in particular as it relates to medical, ethical and economic dimensions. The spectrum of using incentive varies from absolute abandonment to the call for a regulated or even free market of organs from living “vendors”. Recently, there has been a surge in this debate and calls to pilot incentives as means of solving the organ shortage crisis (Matas, 2008; Chapman, 2008; Schicktanz and Schweda, 2009; Godlee, 2008). Riyadh is one of five regions making up the Kingdom of Saudi Arabia (KSA). In 2006 an incentive based scheme for organ donations was introduced in Riyadh. This has resulted in a three-fold increase in the number of donors associated with the activities of the Mobile Donor Action Team (MDAT). Incentives for families of deceased as well as health care workers are used for donor promotion.

**Literature Review:** Several strategies have been utilized throughout the world in order to alleviate this shortage of organs such as public awareness, use of marginal donors, split grafts and optimizing organ distribution policies (Rhee, et. al., 2009; Pomfret, et. al., 2008). The use of incentives as a mean to increase donation has been reported early in the literature (Peters, 1991). The debate continued in the United States (Josefson, 2002) and elsewhere (Godlee, 2008) and is mainly centered on two issues; the first is ethics and morality as they relate to human dignity, exploitation of the poor and viewing human organ as a commodity, and the second is effectiveness of using incentives in a real life situation (Josefson, et. al. 2004). Only scant studies collecting empirical evidence through soliciting public and professional opinion were conducted with conflicting results (Boulware, et. al., 2006; Bryce, et. al., 2005). None of these studies however tested the impact of incentives on the supply of donated cadaveric organs in a real life situation.
**Aim and Objectives:** Using a case study method, the aim is to provide a qualitative review of a three-year incentive-based organ donation system in order to refine the current system and assess transferability to other settings. This will take place in the setting of cadaveric organ transplantation in Riyadh region of Kingdom of Saudi Arabia. Specific objectives are:

4. Review program documents for the last 3 years in order to provide a chronological evolution of the organ donation incentive-based system and identify barriers, facilitators and lessons learned from the process.

5. Utilize key informant interviews and a confirmatory focus group to fill in the gaps and confirm the results from the document review, further assess medical, ethical, religious, cultural and economic issues that have, and may impact the program and also assess issues associated with transferability of the system to other settings.

6. To make recommendations to the transplant community and health authority in Kingdom of Saudi Arabia (KSA) regarding the transferability of the system and areas for further research.

**Research Question:** What are the outcome, feasibility and transferability of employing an incentive-based system on cadaveric organ donation Kingdom of Saudi Arabia (KSA)?

**Method:** A case study of the organ donation system in Riyadh will be reported from 2006 to 2009; when an aggressive approach towards incentives for donors’ families and the health workers dealing with the donation logistic was associated with a three-fold increase in donation rate (statistics will be provided). The methodology is qualitative in which review of pre-existing documents for the last three years of the program will be used to create a chronological audit and to shape interview questions for the sample. Sampling is purposeful and inclusive of all members of team (Mobile Donor Action Team, MDAT) who are employing incentives in the setting of cadaveric organ donation in Riyadh. Short interviews using a semi-structured interview guide will be conducted with the MDAT seven member team (direct implementers of the incentive-based donation system in Riyadh); two interviews with the administrators working with MDAT (focus on management and administrative issues); and one interview with Director of the National Donation Organization to explore the transferability to other region of the Kingdom of Saudi Arabia (KSA). Findings of the interviews will be confirmed by a focus group which will be composed of all subjects. Participants will be asked to sign a consent form. Ethical approval will be sought from University of Liverpool Ethic Committee. Permission to conduct the study will be obtained from Ministry of Health. All interviews will be recorded and transcribed. Transcripts will be analyzed using thematic framework.

**Epistemological Approach:** The study is exploratory in nature, which requires a flexible design that would allow investigation of the pertinent factors and capture the perspectives of health professionals. It adopts an interpretative approach in which peoples’ perspective towards incentives is what determines the decision for donation rather than an “objective reality” Green J & Throgood (2004).

**Research outcome:** The dissertation addresses the question stated by Godlee (2008) in her BMJ editorial: “Is it time to pilot paying for organs?” through critical analysis of incentives for donors and reporting the outcome of an actual pilot project. Subsequently, recommendations will be
made to the transplant community and health authority in Kingdom of Saudi Arabia (KSA) regarding the transferability of the program and areas for further research

**Time table and cost:** Four weeks will be allocated for literature review, another 8 weeks for data collection, and 4 weeks for analysis and another 8 weeks for writing up. Costs related to paper, printing, copying, etc., will be shouldered by the investigator.

**Key References:**


Appendix 5. Questions to respondents and participant information sheet:

The following summarize the line of inquiry in the semi-structured in-depth interview with the participants as well as the confirmatory focus group

1. What are the reasons behind the sharp increase in organ donation in Riyadh over the past 3 years?

2. Describe the role of incentives in creating such an increase:
   a. What kind of incentives worked better?
   b. Who would receive these incentives?
   c. Which part of the process is effective? And with whom?
   d. What are the problems
   e. What other alternatives used?

3. Why do you think the practice of using incentives for the family and health workers to get more organs is morally (i.e. from your point of view) wrong/right?
   a. What harm does inflict? For the donor, donor’s family and society.
   b. What benefit does it invoke? For the donor, donor’s family and society.
4. What are the medical advantages/disadvantages of using incentives to promote organ donation?

5. What do you think are the important ethical issues involved in the use of incentive to promote organ donation? How does this affect your attitude and practice?

6. What is the economic advantage/disadvantage of incentives in promoting organ donation?

7. Why do you think the practice of using incentives for organ donation is permissible/not-permissible from the religious, cultural point of views? How does this affect your attitude and practice?

8. What do you expect will be the problems/opportunities in applying incentive based organ donation in:
   a. The rest of the Kingdom of Saudi Arabia
   b. Middle East.
   c. Western countries.

9. What type of incentives you think is the most effective?

10. What is the degree of satisfaction with the process of using incentives to promote organ donation? How does that affect your practice?

11. Do you have any other concerns or comments?

Thank you.
Participant Information Sheet

Title of the study:
Donor Organ Shortage Crisis: A Case Study Review of an Economic-Incentive System.

Version No and Date: Version 3 on 21st of November 2009

Invitation Paragraph:
You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask me if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with others.

I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thanks for reading this information sheet.

What is the purpose of this study?
As you know, organ transplantation saves the lives of many patients. Organ shortage remains the main challenge to organ transplantation. Many strategies have been tried to solve the problem of organ shortage. The aim of the research you have been asked to participate in is to explore the effectiveness and feasibility of the provision of financial incentive schemes for both health care providers and donor families in the setting of cadaveric organ transplantation to alleviate the problem of organ shortage. I want to explore the impact and ramifications of incentives on cadaveric organ donation based on your most recent experience with incentive-based donation system as has been executed by Mobile Donor Action Team (MDAT) and the degree of your satisfaction with such approach.

Why have I been chosen to take part?
You are part of the team practicing or involved with incentive-based donation system in Riyadh, Saudi Arabia, therefore you were asked to participate in this project. I am asking all members of the team as well as administrators involved to take part in this research.

Do I have to take part?
You do not have to take part in this research project unless you choose to do so. There is explicitly neither obligation nor penalty for not participation. The participation is solely voluntary.

What will happen if I take part?
If you agree on participating then I will conduct a 1 to 1 discussion with you that will last for about 40-60 minutes. This will be recorded with your permission. We will be discussing issues related to the process of organ donation as it relates to incentives. This interview will be
conducted in an office at King Faisal Specialist Hospital and Research Center in Riyadh, Saudi Arabia. Specifically we will be discussing the following areas:

12. The reasons behind the sharp increase in organ donation in Riyadh over the past 3 years.
13. Your views on the role of incentives in creating such an increase.
14. What do you think about the practice and morality of using incentives for the family and health workers to get more organs?
15. What you think the medical advantages/disadvantages of using incentives to promote organ donation are?
16. What you think the important ethical issues involved in the use of incentive to promote organ donation are? and how this affects your own attitude and practice?

Etc

Subsequent to discussing such issues with all team members who agree to participate, I will ask everyone to participate again as a group in 2 hours discussion along the same lines.

The information provided will be accessed by me only. Anonymity will be protected for participants. The information provided will be used only for the purpose of this project. I will be asking you to sign a consent form giving permission to participate in the project.

Expenses and/or payment:
Your participation will be voluntary. There will be no payment or any other materialistic rewards nor any advantages in participating.

Are there any risks in taking part?
There is no physical risk as a result of participation. You may feel some emotional distress when recalling some aspects of organ donation process. If you do, you can inform me during the interview and that can be aborted if you wish.

Are there any benefits in taking part?
Though there is no direct and immediate benefit to you but by understanding the donation motives better through this research, I think this project may be of help to many patients, who are in need of organ transplantation.

What if I am not happy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let me know by contacting [Mohammed Sebayel at +966505448866, Email: mohammed@alsebayel.com and I will try to help. If you remain unhappy or have a complaint which you feel you cannot come to me with then you should contact my Dissertation Advisor Dr. Debora McGill, from University of Liverpool, MPH Online program, Tel: USA (919) 765-9206 Email: deborahmcgill@earthlink.net
**Will my participation be kept confidential?**
The interview will be confidential. It will be recorded and then transcribed. The information provided will be accessed by me only and anonymity will be protected for participants. The information provided will be used only for the purpose of this project. The tapes and transcripts and any other relevant information will be stored and locked securely in my office and stored for maximum of 2 years. After that all transcripts and tapes will be destroyed. Your name or any clues to your identity will not be revealed in the final dissertation.

**What will happen to the result of the study?**
The result of the study will be used to write my master dissertation for the University of Liverpool. If you wish I will provide you with a copy of the dissertation. I might publish some papers based on this research if you wish I can also send copies of these published papers. You will not be identifiable from the result.

**What will happen if I want to stop taking part?**
You can withdraw from the study at anytime, without explanation. Results up to the period of withdrawal may be used, if you are happy for this to be done. Otherwise you may request that they are destroyed and no further use is made of them.

**Who can I contact if I have further questions?**
Mohammed Sebayel, MD  
King Faisal Specialist Hospital and Research Center,  
MBC 72, P.O. box 3354, Riyadh 11211, Saudi Arabia.  
Tel: 0096614424818, or 0505448866  
Fax: 0096614424817 Email: msebyael@kfshrc.edu.sa or mohammed@alsebayel.com
MODEL CONSENT FORM

Title of Research Project: Donor Organ Shortage Crisis: A Case Study Review of an Economic-Incentive System.

Researcher(s): Mohammed Sebayel

Please initial box

1. I confirm that I have read and have understood the information sheet dated [21st of October 2009] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.

3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.

4. I agree to take part in the above study.

Participant Name

________________________________________________________________________

Date

Signature

Name of Person taking consent

Mohammed Sebayel

________________________________________________________________________

Date

Signature

Researcher

Mohammed Sebayel

________________________________________________________________________

Date

Signature

The contact details of lead Researcher (Principal Investigator) are:

[Mohammed Sebayel, MD
King Faisal Specialist Hospital and Research Center,
MBC 72, P.O. box 3354, Riyadh 11211, Saudi Arabia.
Tel: +96614424818 or +966505448866 Fax: +96614424817
Email: msebyayel@kfshrc.edu.sa or mohammed@alsebayel.com]
Appendix 6. Ethical approvals UoL.

---

**Subject:** RE: The Final Ethic Application For Review

**Author:** Lars Smith  
**Posted date:** Thursday, November 26, 2009 5:40:33 AM EST  
**Last modified date:** Thursday, November 26, 2009 5:40:33 AM EST  
**Total views:** 8  
**Your views:** 5

---

**Author:** Mohammed Sebayel  
**Date:** Saturday, November 21, 2009 9:18:06 AM EST  
**Subject:** The Final Ethic Application For Review

Hi Deb,

These are the final documents.

Mohammed

1. proposal.doc
2. questions.doc
3. consent.doc
4. participnat information sheet.doc
5. ethical application.doc

LETTER OF APPROVAL - DR. EZZAT.pdf
LETTER OF APPROVAL - DR. SHAEHEEN.pdf

I, Lars Smith, approve this proposal.

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**Subject:** RE: The Final Ethic Application For Review
Appendix 7. Permissions of MOH and KFSH&RC.

01 November 2009

LETTER OF APPROVAL

To Whom It May Concern:

After reviewing the attached dissertation proposal of Dr. Mohammed Sebayel entitled “Donor Organ Shortage Crisis: A Case Study Review of an Economic-Incentive System”, I highly recommend to proceed with the study as outlined in the proposal and be accepted in partial fulfillment of the requirements for the Master Degree of Business Administration, with a major in Public Health of Dr. Sebayel.

Thank you.

Respectfully Yours,

Adnan Ezzat, MD
Executive Director
Medical & Clinical Affairs
01-November-2009

LETTER OF APPROVAL

To Whom It May Concern:

After reviewing the attached dissertation proposal of Dr. Mohammed Sebayel entitled "Donor Organ Shortage Crisis: A Case Study Review of an Economic - Incentive System", I highly recommend to proceed with the study as outlined in the proposal and be accepted in partial fulfillment of the requirements for the Master Degree of Business Administration, with a major in Public Health of Dr. Sebayel.

Thank you

Respectfully yours

Faisal M.A. Shaheen, MD
Director General
Saudi Center for Organ Transplantation
13 June 2010

To Whom It May Concern:

After reviewing the attached proposal of Dr. Mohammed Sebayel entitled “Donor Organ Shortage Crisis: A Case Study And Review Of An Economic Incentive System” I give him permission to access Mobile Donor Action Team documents in order to complete his study as outline in partial fulfillment of the requirements for the Master Degree In Public Health for Dr. Mohamed Sebayel.

Sincerely,

Talal Al Aqeel
Director of Mobile Donor Action Team

13 Jun 2010
END