

# Public Private Partnership-based performance management in fragmented healthcare systems: the case of organ donation and transplantation in Lebanon

Joumana Stephan

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# THESE DE DOCTORAT DE

#### NANTES UNIVERSITE

ECOLE DOCTORALE N° 597 Sciences Economiques et sciences De Gestion Spécialité : « Sciences de Gestion »

Par

« Joumana STEPHAN YERETZIAN »

## « PUBLIC PRIVATE PARTNERSHIP-BASED PERFORMANCE MANAGEMENT IN FRAGMENTED HEALTHCARE SYSTEMS»

« THE CASE OF ORGAN DONATION AND TRANSPLANTATION IN LEBANON »

Thèse présentée et soutenue à « Nantes », le « 21 juillet 2022 » Laboratoire d'Economie et de Management Nantes-Atlantique LEMNA **IAE Nantes Economie & Management** 

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My PhD experience came late in life with more maturity and a need to engage in a cerebral activity and accomplish a personal challenge. It was a long and eventful journey but definitely a fruitful one as it allowed me to learn more about myself as a person first and foremost, but also in terms of my capacity for research, critical thinking, writing and of course handling stress.

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## LIST OF ABBREVIATIONS

ABM Agence de la Biomédecine

ALDOR Lebanese Association for Organ and Kidney Donation and Transplantation

CMS Centers for Medicare and Medicaid Services

DCD Donors after Circulatory Death

DD Deceased Donor

DG Director General

DoT Division of Transplantation

DSA Donation Service Area

DTI Donation and Transplantation Institute

EU European Union

GDP Gross Domestic Product

GODT Global Observatory on Donation and Transplantation

HAS Higher Authority for Health

HIV Human Immunodeficiency Virus

HHS Department of Health and Human Services

HRSA Health Resources and Services Administration

ICU Intensive Care Unit

IRODaT International Registry on Organ Donation and Transplantation

IRA Independent Regulatory Agency

LOP Lebanese Order of Physicians

LRD Living Related Donation

LURD Living Unrelated Donation

MENA Middle East and North Africa

MESOT Middle East Society for Organ Transplantation

MOH Minister of Health

MoPH Ministry of Public Health

NC National Coordinator

NGO Nongovernmental Organizations

NOD-Lb National Organization for Organ and Tissue Donation and Transplantation

NOTA National Organ Transplant Act

NPG New Public Governance

NPM New Public Management

NSSF National Social Security Fund

OECD Organization for Economic Co-operation and Development

ONT Organización Nacional de Trasplantes

OPO Organ Procurement Organization

OPTN Organ Procurement and Transplantation Network

PI Performance Indicators

pmp per million population

PMSs Performance Management Systems

PPP Public Private Partnership

SEUSA Spanish, European and USA

SRA Regulatory and Support Services

SRTR Scientific Registry of Transplant Recipients

TCE Transaction Cost Economics

TPM Transplant Procurement Management

UAGA Uniform Anatomical Gift Act

UK United Kingdom

UNDP United Nations Development Programme

UNOS United Network for Organ Sharing

USA United States of America

USAID United States Agency for International Development

USD United States Dollar

WHO World Health Organization

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# **CONDENSE DE LA THESE**

A une ère marquée par une forte transition épidémiologique et une montée soutenue des maladies non transmissibles, la transplantation d'organes s'affirme comme la solution de dernier recours pour traiter la défaillance d'organes (Klein et al., 2010; Roels & Rahmel, 2011; Rudge et al., 2012) présentant des avantages significatifs en termes de coûts (Axelrod et al., 2018; Barnieh et al., 2011; Jones & Bes, 2012; Winkelmayer et al., 2002) au niveau global du système de santé. Cependant, l'incapacité dans laquelle se trouvent la plupart des pays à prélever des organes en nombre suffisant génère un problème majeur face à une demande d'organes croissante (Bilgel, 2011; Delmonico et al., 2011; Howard et al., 2007; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999). Face à cette pénurie, la plupart des travaux sur le don et la transplantation d'organes se concentrent sur l'augmentation du nombre d'organes disponibles à partir de l'élaboration d'une législation et du maintien des normes éthiques, ainsi qu'en proposant des approches marketing pour encourager le don et augmenter le nombre de transplantations. En revanche, peu d'attention a été accordée au management de la performance du processus de don et de la transplantation d'organes.

En s'inspirant des doctrines de la Nouvelle Gouvernance Publique, cette recherche apporte une contribution originale à l'analyse et la compréhension des questions portant sur le don et la transplantation d'organes en mobilisant un cadre, basé sur la valeur, proposé par Bao et al. (2013) qui met l'accent sur l'importance de la gouvernance et du management dans la création de biens publics. Il est clair que divers facteurs ont un impact sur le management de la performance (Arnaboldi et al., 2015). Ces facteurs

découlent de la complexité du contexte et incluent, le degré de fragmentation du système de santé, le niveau d'accès à la santé universelle, la source de financement, le nombre de décisions et de décideurs, l'orientation et la stabilité politiques, la quantité d'efforts collaboratifs et les organisations impliquées. Ainsi, les systèmes de santé fragmentés où les soins sont basés sur différents systèmes et sont dispensés par plusieurs prestataires mal coordonnés (Agha et al., 2017) dans des pays fragiles qui sont fréquemment soumis à la violence et aux conflits, à l'instabilité politique, à la mauvaise gouvernance, à l'extrême pauvreté, aux crises de réfugiés et même les catastrophes naturelles (Hill et al., 2014) sont d'un intérêt particulier compte tenu des défis organisationnels supplémentaires qu'ils présentent (Cebul et al., 2008 ; Fadi Abou-Mrad & Tarabey, 2014 ; Stange, 2009).

Ainsi, la contribution scientifique de cette thèse se concentre sur la compréhension des questions de gouvernance, en appui sur le cadre de gouvernance de la santé de Mikkelsen-Lopez (2011)) et de management de la performance (en utilisant le cadre d'analyse proposé par Ferreira et Otley (2009)) dans la prestation d'un service public, à savoir le don et la transplantation d'organes. L'originalité de cette thèse réside aussi sur le fait qu'elle traite des systèmes de santé fragmentés en contexte fragile. Ainsi, la question principale de recherche à laquelle cette thèse souhaite répondre est : « Quel modèle de management de la performance peut-on proposer pour un système de prélèvement et de transplantation d'organes dans un contexte de santé fragmenté et fragile ? ». Cette question se décline en quatre sous-questions comme suit :

- Comment définir la performance d'un système de don et de transplantation d'organes ?
- Quels enjeux de performance peut-on identifier dans un système de don et de transplantation d'organes dans un contexte de santé fragmenté en contexte fragile ?
- 3. Comment analyser un PPP comme une solution de gouvernance et de régulation aux problèmes de management de la performance des systèmes de don et de transplantation d'organes ?
- 4. Quelle contribution à la résolution des problèmes de gouvernance et de régulation soulevés par les PPP dans un système de don et de transplantation d'organes, la littérature sur le contrôle inter-organisationnel peut-elle apporter ?

Le Liban étant un exemple emblématique d'un pays en fragilité et en transition (Ammar et al., 2016; Asmar, 2011; Khalife et al., 2017), c'est son système de don et de transplantation d'organes qui a été choisi comme terrain empirique de cette recherche. Le pays a passé les 30 dernières années à se remettre des dommages infligés par une guerre civile de 15 ans qui l'a laissé aux prises avec l'inflation, la dégradation de ses services publics, l'exode de ses ressources humaines et la destruction de ses infrastructures (Kronfol & Bashur, 1989). De plus, la faiblesse et la fragmentation inhérentes au système ont été encore plus exacerbées par la crise des réfugiés syriens, qui a augmenté la population libanaise d'environ 30 % en 3 années et a exercé une

pression sur les infrastructures, les prestations de services et les finances publiques du système de santé (Ammar et al., 2016 ; Habib, 2019).

#### Méthodologie

Cette recherche s'appuie sur une étude de cas empruntant aux méthodologies qualitatives et à un paradigme interprétativiste. Afin d'explorer le management de la performance du don et de la transplantation d'organes dans un contexte fragmenté et fragile, cette thèse se concentre sur un seul cas à savoir, le système libanais de don et de transplantation d'organes. L'analyse est étayée par l'examen d'une série de grands systèmes de don et de transplantation d'organes de différents pays à savoir les États-Unis, l'Espagne, la France et la Turquie, conduisant à mettre en évidence les problèmes de gouvernance potentiels inhérents à ces différents systèmes. Le choix des pays a été fait en fonction de leurs taux de donation ainsi que des diverses caractéristiques régionales et culturelles, mais aussi en raison de leurs influences ou similitudes avec le modèle libanais.

La collecte de données secondaires a consisté en l'étude de différents documents : études évaluées par des pairs, rapports administratifs et sites Web liés aux dons d'organes spécifiques à chaque pays. Des données ont également été recueillies en consultant des sites Web mondiaux sur le don d'organes, notamment le Global Observatory on Donation and Transplantation (GODT), le International Registry of Organ Donation (IRODat) et le Donation and Transplantation Institute (DTI).

En ce qui concerne les sources primaires portant directement sur le système libanais, des entretiens semi-structurés ont été menés avec des membres de l'Organisation nationale libanaise pour le don et la transplantation d'organes et de tissus (NOD-Lb) et le ministère libanais de la Santé publique (MoPH) afin d'avoir une compréhension de leurs rôles, de la hiérarchie et du fonctionnement de NOD-Lb ainsi que des caractéristiques de leur collaboration avec le MoPH. Les entretiens, recueillis en langue arabe ont ensuite été retranscrits et analysés à l'aide d'une analyse thématique pour identifier les thèmes récurrents. Les entretiens semi-directifs ont été complétés par des entretiens informels qui ont permis d'approfondir et de clarifier certains concepts. La validité des résultats a été assurée par la triangulation des données primaires et primaires-secondaires. La rigueur de l'étude a été renforcée par la réflexivité du chercheur, en adoptant une posture d'audit et d'explicitation systématique des présupposés rencontrés, et en fournissant des descriptions détaillées (thick data) et des déclarations textuelles à valider par les participants.

#### Résultats

Les résultats de cette thèse seront présentés en lien avec la question de recherche à laquelle ils répondent.

 Comment définir la performance d'un système de don et de transplantation d'organes ?

Convoquant le cadre de gouvernance de Mikkelsen-Lopez (2011), nous proposons de catégoriser les systèmes de don et de transplantation d'organes dans différents pays sous trois rubriques principales : société et culture, gouvernance et prestation de

services. L'analyse de ces systèmes permet de démontrer l'importance clé des questions de gouvernance et plus spécifiquement, de caractériser le type de régulation proposé mobilisant une agence, et la nature de la collaboration entre les secteurs public et privé. Parmi les exemples de différents mécanismes de gouvernance figurent les partenariats public-privé (PPP), et les agences et unités publiques au sein du ministère de la Santé. Cette variabilité découle des différences en matière de systèmes de santé, d'idéologies politiques et de valeurs culturelles. Alors que des agences publiques ou les services du ministère réglementent le processus de don d'organes dans les systèmes de santé publics, un mécanisme de gouvernance basé sur les PPP semble être plus approprié dans les systèmes de santé privés.

De plus, le recours au cadre « Perfomance Management Systems (PMSs) » de Ferreira & Otley (2009) permet de structurer et d'organiser les informations collectées pour construire la vision globale des stratégies de l'organisation, facilitant l'analyse de leur mise en œuvre et l'identification des mécanismes d'amélioration du système (Ferreira & Otley, 2009). Les résultats de cette analyse montrent que les pays étudiés ont identifié une mission et sont porteurs d'une vision en matière de don et de transplantation d'organes clairement énoncées. Ils peuvent s'appuyer sur une organisation structurée et des plans stratégiques détaillés qui leur permettent de définir des facteurs de succès, de fixer des objectifs et d'évaluer des indicateurs de performance. De plus, ils ont conçu des mécanismes pour évaluer leurs performances et améliorer leurs systèmes en conséquence.

Quels enjeux de performance peut-on identifier dans un système de don et de transplantation d'organes dans un contexte de santé fragmenté et fragile ?

En utilisant le cadre d'analyse de Ferreira et Otley (2009), nous démontrons que le principal défi du système libanais de don et de transplantation d'organes réside dans sa gouvernance et la nécessité de lui appliquer des systèmes de management de la performance. Les tableaux ci-dessous proposent une présentation synthétique des problèmes du système libanais de don et de transplantation d'organes et de leurs conséquences classés selon le cadre de gouvernance (tableau 1) et mettent en évidence les lacunes du système du point de vue du management de la performance (tableau 2).

Tableau 1 : les problèmes du système libanais de don et de transplantation d'organes et leurs conséquences classés selon le cadre de gouvernance proposes par Mikkelsen-Lopez (2011).

Niveau de gouvernance	Problèmes	Conséquences
Prestation de service	Des retards dans les processus légaux Des retards dans le processus Des difficultés de communication avec les parents Une prise en charge dégradée des organes Une liste d'attentes incomplète Rapports d'intervention incomplets Des politiques hospitalières contradictoires Absence de protocole de résolution de problèmes	Perte d'organes viables Refus de faire un don Entrave le processus d'évaluation Faible collaboration Faibles taux de donation
Gouvernance	Une loi obsolète et mal formulée Un système de santé fragmenté Un système financier bloquant Une déficience en matériel et infrastructure Une insuffisance en ressources humaines Des reportages médiatiques inexacts Un manque de stabilité de continuité et d'engagement Une large présence de corruption	Développement lent Activités de dons et de transplantation réduites Confiance dégradée dans les pouvoirs publics Processus de décision bloqué Goulets d'étranglement Inégalité d'accès Faibles taux de donation
Society	Un manque d'engagement des professionnels de la santé La religion Un manque d'information et d'engagement de la part du public Primauté des intérêts privés et personnels sur l'intérêt général - Clientélisme	Faibles taux de donation

Tableau 2 : Le modèle libanais de dons d'organes vu au prisme du cadre analytique des Systèmes de Management de la Performance (SMP) de Ferreira & Otley (2009)

Dimensions du SMP	Modèle Libanais
Vision et Mission	Sauver et améliorer la vie d'autant de personnes que possible au Liban grâce au don et à la transplantation d'organes et de tissus
	Augmenter le taux de don d'organes et de tissus pour atteindre l'autosuffisance grâce à la mise en œuvre d'un modèle libanais de don et de transplantation d'organes et de tissus
Facteurs clés de succès	Augmenter les taux de donation d'organes
(FCS)	Création d'un laboratoire national de don d'organes Atteindre une autosuffisance nationale en matière de don d'organes
Structure de pilotage	PPP (MoPH & NOD-Lb)
	Membres du Conseil
	Coordination à 3 niveaux (national, régional, hospitalier)
Stratégies et plans	Non disponible pour le moment
Indicateurs clés de	Nombre de transplantations par source et organe
performance (ICP)	Taux de conversion
	Nombre de patients sur liste d'attente
	Nombre de cartes de don
	Taux de consentement des familles
Objectifs Fixés	Interne, taux de don d'organes de 20 donneurs/million d'habitants d'ici 2020
Evaluation des	Planifier des audits hospitaliers
Performances	NOD-Lb Audités par des agences internationales
Système de récompense	Non utilisé mais à inclure dans l'accréditation des hôpitaux
Flux d'informations,	Réunions ad hoc au besoin
systèmes et réseaux	
SMP utilisés	Non utilisés
Evolution des SMP	Ne peut être évaluée

# 3. Comment analyser un PPP comme une solution de gouvernance et de régulation aux problèmes de management de la performance des systèmes de don et de transplantation d'organes ?

En tant qu'organisme de régulation indépendant, le fonctionnement de NOD-Lb combine des éléments relevant de la théorie de l'agence et de la théorie de l'intendance (stewdardship). NOD-Lb se caractérise par une séparation structurelle, une autonomie

de management, mais pas de responsabilité managériale. Ce dernier point devient redondant lorsqu'il est combiné à des besoins d'ordre supérieur, à une motivation intrinsèque, à un engagement de grande valeur et à un pouvoir personnel dû à l'expertise. Cela engendre la confiance et un engagement à long terme qui minimise le besoin de mécanismes de responsabilisation stricts qui font généralement partie intégrante des accords de PPP traditionnels. Au Liban, cependant, cela n'a pas été jugé nécessaire car NOD-Lb ne prend aucune décision bilatérale. Une autre explication réside dans la dualité du contexte libanais qui se caractérise par le collectivisme d'une part et la distanciation au pouvoir d'autre part.

En utilisant le modèle de partenariat de Brinkerhoff (2002), la collaboration entre le MoPH et NOD-Lb peut être décrite comme un partenariat organisationnel et une mutualité qui est basée sur la confiance et les relations personnelles institutionnalisées. En fait, la collaboration reste ad hoc avec des réunions programmées en fonction des besoins. Il semble que la collaboration soit en fait motivée par une attitude de laisserfaire selon laquelle le MoPH n'intervient que s'il est nécessaire de ratifier une nouvelle loi ou de discuter d'un nouveau budget. Essentiellement, le processus est régi et mis en œuvre par le régulateur, qui est l'expert en la matière, avec l'approbation du MoPH, mais sans toutefois avoir l'autorité ou le pouvoir d'appliquer les règles. De toute évidence, cela désavantage le régulateur car en l'absence de moyens formels pour imposer la réglementation, il doit s'appuyer sur des relations personnelles et des réseaux personnels.

4. Quelle contribution à la résolution des problèmes de gouvernance et de régulation soulevés par les PPP dans un système de don et de transplantation d'organes, la littérature sur le contrôle interorganisationnel peut-elle apporter ?

Le modèle libanais de gouvernance des PPP semble être statique dans le temps avec peu d'évolution dans les facteurs de contingence ou les mécanismes de contrôle. Essentiellement, l'étape de prise de contact semble être le moteur en termes de management de la collaboration. Par ailleurs, la plupart des mécanismes qui ont été mis en place au début de la collaboration ont persisté et sont restés inchangés avec le temps. Compte tenu de l'importance de la phase de contact, un examen plus approfondi de cette phase est justifié à travers le modèle proposé par Langfield-Smith (2008).

Les réformes du système de santé et le mouvement vers une gouvernance collaborative basée sur l'expérience antérieure ainsi que le rôle des relations personnelles et des arrangements informels dans la culture libanaise ont été à la base de la structure de gouvernance établie et des processus de contrôle de management mis en place à l'époque. Les mécanismes de gouvernance et de contrôle sont tous deux déterminés par la confiance et par des variables explicatives, puis restent statiques pendant toute la durée du PPP en l'absence de processus visant à améliorer la confiance et à atténuer les risques. La gouvernance ne semble pas avoir d'impact sur les mécanismes de contrôle. Cela coïncide avec l'analyse du cadre des SMP où les mécanismes formels d'évaluation de la performance sont inexistants.

La situation libanaise suggère une reformulation du modèle proposé par Langfield-Smith (figure 1) qui intègrerait les conclusions basées sur le modèle libanais de PPP pour la gouvernance du don d'organes. Les éléments surlignés en jaune sont des ajouts au modèle initial tandis que ceux en rouge sont manquants.

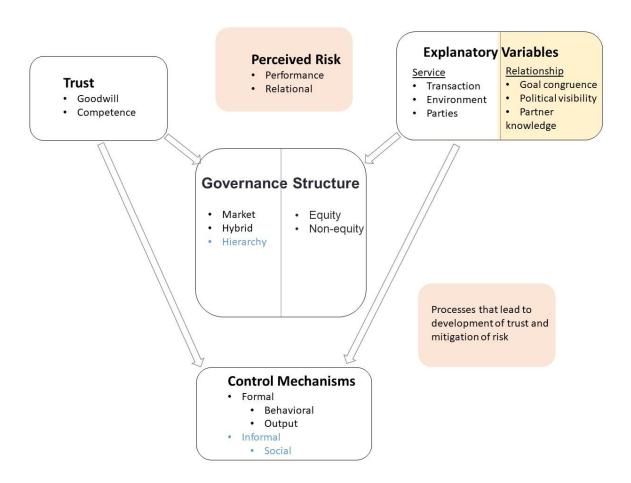


Figure 1: Le modèle de Langfield-Smith d'influences des mécanismes de contrôle interentreprises adapté au PPP pour la gouvernance du don et de la transplantation d'organes au Liban

#### **Contributions**

La thèse offre plusieurs contributions sur les perspectives managériales, théoriques, méthodologiques et pratiques.

D'un point de vue **managérial**, l'apport principal de cette thèse consiste à :

- Aborder le concept de gouvernance du don et de la transplantation d'organes qui, bien qu'étant au premier plan de la plupart des discussions sur la santé publique, fait défaut dans les écrits sur le don d'organes.
- Combiner les composantes des théories de l'agence et de l'intendance
   (stewardship) pour proposer le profil d'une agence de régulation hybride pour le
   don et la transplantation d'organes dans un système de santé fragmenté
   évoluant dans un environnement fragile.
- Mobiliser la littérature de contrôle inter-firmes pour revisiter les questions de gouvernance basées sur les PPP du modèle de don et de transplantation d'organes dans un contexte fragmenté et fragile.
- Positionner l'analyse du PPP pour la gouvernance du don et de la transplantation d'organes comme un problème potentiel de management de la performance en mettant en évidence l'importance des caractéristiques de service et de relation ainsi que les rôles de la confiance et du risque perçu dans le choix de la gouvernance dans un système de santé fragmenté et de surcroît dans un cadre fragile.

D'un point de vue théorique, l'apport principal de cette thèse consiste à :

- Compléter l'analyse de la gouvernance des systèmes de don et de transplantation d'organes selon la perspective de la théorie de l'économie des coûts de transaction en incluant parmi les variables explicatives, des variables relationnelles particulièrement applicables aux contextes fragmentés et fragiles.
- Mettre en évidence dans la littérature du secteur public les mérites des nouveaux cadres de gouvernance publique pour expliquer le rôle de la gouvernance sur le management de la performance dans la prestation de services de biens publics.
- Contribuer à la littérature sur les PPP et les agences de régulation et aux recherches en cours sur la collaboration entre l'État et les organisations à but non lucratif ainsi que sur le rôle de l'agence.
- Offrir de nouvelles perspectives à la recherche sur le don et la transplantation d'organes en analysant les problèmes du système sous un angle de management de la performance.

D'un point de vue **méthodologique**, l'étude du don d'organes selon une approche qualitative et une méthodologie d'étude de cas a permis d'approfondir et d'explorer les enjeux relevant du management de la performance des systèmes de don et de transplantation d'organes. La plupart des études sur le don d'organes à ce jour étant de nature plus épidémiologique, se sont concentrées principalement sur des informations numériques et des statistiques relatives au potentiel de donneurs décédés, aux taux de conversion, aux taux de consentement et au nombre de donneurs gagnés ou perdus à

chaque phase. De plus, la plupart des études s'inscrivent au sein du paradigme positiviste et sont menées à partir d'approches quantitatives.

D'un point de vue **pratique**, les apports de cette thèse consistent à :

- Fournir un modèle de description des influences sur le management de la performance adapté au PPP pour la gouvernance du don et de la transplantation d'organes dans un système de santé fragmenté dans un contexte fragile.
- Proposer un cadre pour l'analyse de l'agence de régulation et de la collaboration au sein d'un PPP pour la gouvernance du don et de la transplantation d'organes dans un système de santé fragmenté dans un contexte fragile.
- Proposer un cadre pour analyser des systèmes de gouvernance et de management de la performance en matière de don et de transplantation d'organes.
- Analyser un système de don et de transplantation d'organes dans un système de santé fragmenté dans un contexte fragile.

#### **Implications**

Plusieurs recommandations émanent de l'analyse présentée dans cette thèse. Elles sont détaillées sur trois niveaux à savoir, le MoPH, l'agence de régulation NOD-Lb et la société au sens large.

Au niveau du ministère, il est important de développer des mécanismes de contrôle inter-organisationnels évolutifs associés à un mécanisme de gouvernance qui intègre une évaluation du risque perçu, ainsi que des processus qui favorisent l'instauration de la confiance. L'importance de la confiance dans le choix des mécanismes de gouvernance au Liban suggère la nécessité d'une analyse plus approfondie des questions de confiance qui vont au-delà de la confiance dans les parties et incluent une analyse des déterminants des systèmes et des institutions de confiance (Greenberg et al., 2008).

Le système de don et de transplantation d'organes doit développer des systèmes de management des performances appropriés qui comprennent un plan stratégique solide avec des objectifs, des indicateurs de performance et, plus important encore, des mécanismes d'évaluation des performances et une compréhension claire de la manière dont les SMP sont utilisés et apportent des changements.

Cet effort qui a commencé comme une initiative de la société civile en raison d'un système public faible et d'un manque d'expertise, doit évoluer vers un service public fourni par le gouvernement. Pour ce faire, le ministère de la Santé publique doit intégrer

le programme dans le cadre de son plan national de santé et développer les capacités et l'expertise nécessaires pour diriger le programme au niveau politique tout en en déléguant la mise en œuvre à une entité privée dans l'esprit d'un partenariat public-privé, où le partenaire bénéficie d'un soutien total et dispose du pouvoir d'initier les actions nécessaires. Il devrait y avoir un département au sein du ministère de la Santé publique concerné par le don d'organes qui comprenne des professionnels ayant l'expertise appropriée pour donner des avis éclairés et prendre des décisions pertinentes.

La collaboration entre le MoPH et NOD-Lb doit s'étendre au-delà des rencontres personnelles entre deux ou trois personnes. Elle devrait être formalisée pour devenir plus qu'un acte de recherche d'approbation et de ratification. En outre, les réunions doivent être planifiées régulièrement et doivent inclure à la fois les coordinateurs nationaux et régionaux.

Pour assurer un financement et un remboursement adéquats du système ainsi qu'un contrôle et un pouvoir sur les différentes composantes, il est nécessaire de promouvoir une santé universelle qui englobe le don d'organes et en reconnaisse la nécessité. Des incitations financières appropriées doivent être étudiées et proposées au Liban, d'autant plus que la plupart des professionnels de la santé se trouvent dans des hôpitaux privés, il est important de promouvoir les activités d'approvisionnement et de transplantation dans les hôpitaux publics à travers un projet de jumelage avec les hôpitaux privés. Les

hôpitaux privés peuvent également être encouragés à participer par le biais d'incitatifs financiers et des programmes de contrôle de la qualité.

Les objectifs et les buts des partenaires doivent être correctement alignés afin de créer une valeur ajoutée et d'offrir ce service indispensable. Pour que le processus fonctionne correctement, il nécessite un soutien, des ressources et des infrastructures adéquates, dépendant tous de l'engagement des deux partenaires. Le processus doit bénéficier d'une stabilité indépendamment de la situation financière et politique du pays. Le budget et le soutien fournis par le ministère de la Santé ne doivent pas dépendre de l'année ni de l'agenda politique ou des affiliations du ministère de la Santé.

En ce qui concerne l'agence de régulation, l'accent doit être mis sur la décentralisation des actions, la redistribution des rôles et la division du travail. La mise en œuvre du processus de don d'organes ne peut dépendre de la volonté de quelques personnes choisies et dévouées, mais doit devenir un exercice de collaboration à part entière qui inclut la société dans son ensemble. De plus, il devrait y avoir un système intégré d'assurance qualité et de responsabilité engagée dans le cadre du processus de collaboration et de coordination. Il doit être entrepris comme une expérience d'apprentissage afin de prévoir les ruptures potentielles dans le processus et de mettre en œuvre des améliorations.

Au plan de la société, les professionnels de la santé et les administrateurs hospitaliers devraient s'investir davantage et participer plus activement au processus. Les

coordinateurs régionaux et locaux doivent être habilités et autorisés à s'engager à un niveau supérieur. Ils devraient être correctement rémunérés pour leurs efforts, mais ils devraient également comprendre l'importance des tâches à accomplir et être conscients de la grande valeur de leur rôle pour sauver des vies. Les juges doivent être mieux formés et des efforts doivent être déployés pour régler les affaires en temps opportun afin d'éviter la perte d'organes ou de limiter le consentement de la famille.

Les médias devraient être plus impliqués et les informations correctement canalisées.

Dans un esprit de sensibilisation et de promotion de la transparence, les médias devraient être formés, régulièrement informés et activement engagés dans les activités liées au don et à la transplantation d'organes. Le don d'organes n'est pas qu'une question de scoops et d'émotions. Enfin, la société libanaise doit être responsabilisée et informée. L'opinion publique doit comprendre l'importance du programme et être autorisée à contribuer au processus. Cela pourrait être réalisé en impliquant le public dans le processus de prise de décision et de planification (Danet et al., 2021).

# INTRODUCTION

In an aging society where health is transitioning from communicable towards non-communicable diseases, organ transplantation plays an important role as it is considered the last resort treatment for curing chronic organ failure (Klein et al., 2010; Roels & Rahmel, 2011; Rudge et al., 2012; Tiessen et al., 2008; Vanholder et al., 2021). In addition to prolonging the lifespan of patients, organ transplantation has been shown to provide substantial cost benefits to a country's health care system (Axelrod et al., 2018; Barnieh et al., 2011; Jones & Bes, 2012; Tiessen et al., 2008; Vanholder et al., 2021; Winkelmayer et al., 2002). Paradoxically, the continued success of transplantation procedures is the main driver behind the increase in demand on organs (Bilgel, 2011; Tiessen et al., 2008). Therefore, there continues to be a considerable disparity between organ availability and demand as countries fail to proceure enough organs (Bilgel, 2011; Delmonico et al., 2011; D. H. Howard et al., 2007; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999; Tiessen et al., 2008).

Although a public health problem, countering the organ shortage is in line with the continuous economic struggle between supply and demand (Bilgel, 2011). In order to address the paucity in organs, one must simultaneously decrease the demand while increasing the supply (Delmonico et al., 2011; Roels & Rahmel, 2011). Reducing demand entails lowering the need for transplantation which is achieved first through the prevention of organ failure and the promotion of healthy living and second through the anticipation of organ rejection by ensuring rigorous and compatible organ matching as well as providing continuous care and maintenance post transplantation (Roels &

Rahmel, 2011; Vanholder et al., 2021). As for increasing availability, there are, in essence, two methods for securing organs one through live donation and the other through deceased procurement (Rudge et al., 2012; Tiessen et al., 2008; Vanholder et al., 2021). However, both methods are fraught with moral dilemmas and pose numerous ethical challenges including the exploitation of vulnerable populations, the reduction of organ trafficking as well as overcoming religious and cultural objections and fears. Therefore, balancing organ supply with demand entails approaching the problem from three angles: (1) an ethical perspective by adapting the laws and the consent processes, (2) a marketing perspective by enlarging the donor pool through the use of different types of donors, the promotion of public awareness and the training of health professionals, and finally (3) a performance management perspective by addressing good governance and regulation as well as enhanced interorganizational collaboration and control. Yet, the research on organ donation and transplantation has traditionally focused on increasing the quantity of organs available while little attention has been directed towards the performance of different models of organ donation and transplantation and the management of the process as a whole.

Since most efforts to date have approached organ donation and transplantation from the ethical and marketing perspectives primarily concentrating on country legislature and donor characteristics in an attempt to increase the availability of organs, this thesis will seek to address this first gap in the literature by proposing to analyze the organ donation and transplantation system from a performance management perspective. In fact, organ donation and transplantation will be considered as a system whose

performance can be measured and managed in order to assess and develop areas potentially in need of improvement. Good management of the organ donation and transplantation process along with good governance is thus primordial as the process is complex, involves multiple, lengthy, unpredictable procedures and encompasses a large network of individuals with varying backgrounds and specialties that are collaborating towards a common goal (Bilgel, 2011; Manzano & Pawson, 2014; Miranda, Naya, et al., 1999; Tiessen et al., 2008). Therefore, it is important to optimize the system of organ donation and transplantation in order to efficiently and equitably utilize all donated organs (Vanholder et al., 2021). Moreover, the organ donation and transplantation process is not merely about medical expertise and the availability of resources (Delmonico et al., 2011; Miranda, Naya, et al., 1999; Usul et al., 2020) but rather, it is to a large extent dependent on the commitment and involvement of both the government and society. Thus, for the system to work, it has to combine an appropriate legal framework with medical expertise and good organizational support. The need for the latter compounded by the scarcity of organs available for donation makes the implementation of performance management systems and good governance mechanisms a necessity for any organ donation and transplantation system (Miranda, Naya, et al., 1999).

This situation has prompted the World Health Organization (WHO) to issue a directive for countries to strive towards a state of self-sufficiency in terms of the organ donation and transplantation needs of their citizens (Delmonico et al., 2011; Matesanz, Domínguez-Gil, et al., 2011; Vanholder et al., 2021; WHO et al., 2011; Wynn &

Alexander, 2011). Countries worldwide have been actively engaged in managing their organ donation and transplantation processes in an attempt to improve their donation and transplantation rates (Vanholder et al., 2021; Živčić-Ćosić et al., 2013). Yet, to date, there appears to be no single system best capable of managing organ donation and transplantation in the world. Rather, each country has proposed individualized solutions in an attempt to resolve the organ shortage that it faces. Keeping in mind the difficulty of realizing this aim while adhering to strict ethical principles and maintaining societal trust (Rodríguez-Arias et al., 2010), countries have been propelled to devise appropriate management strategies to increase and maintain their organ donation and transplantation rates (Tiessen et al., 2008; Vanholder et al., 2021).

Moreover, organ donation and transplantation is a public service and therefore the issues in the process of donation and transplantation should be approached within the realm of the public sector. In fact, New Public Governance (NPG) doctrines which places the values that it aspires to meet at the center of the governance debate and focus on mechanisms for building trust and legitimacy (Bao et al., 2013; Bryson et al., 2014; McMullin, 2021; O'Flynn, 2007; Osborne, 2006), appear to be particularly well-suited for the analysis of organ donation and transplantation processes. This suggests that a value-based model that combines governance and performance management in the creation of public goods and the provision of public services seems to be required for addressing the challenges and problems that governments face in meeting the organ donation and transplantation needs of their citizens while taking into account the uniqueness of their contextual setting, the specificities of the problem to be solved and

the alignment of political goals and culture-specific values (Angelé-Halgand & Garrot, 2015; Bao et al., 2013). NPG doctrines with their emphasis on the creation of value through a co-production process that recognizes the importance of the collaboration between the public, the private and the non-profit sectors (Bao et al., 2013), join, in this instance, the public health research calling for intersectoral collaboration that even extends towards involving citizens in public health initiatives at various levels as a means of improving inequalities in healthcare provision (Danet et al., 2021; Lombrail, 2016).

Furthermore, the value-based framework for performance management and governance, and leadership that is exploited in this thesis stresses the importance of the setting, with higher performance evident when governments adapt their policy and leadership strategies to the type of problem paying special attention to whether the difficulty lies in the complexity of the problem or as a result of conflicting values (Bao et al., 2013). Working in the public sector and in particular within the healthcare context is complex in and of itself. Add to it an extra layer of complexity due to the contextual setting of interest and it becomes clear that what appears to be a viable solution in one culture and economy does not necessarily function in the same way in another and efficient performant systems are not necessarily transportable (Matesanz, 2003; Shaheen, 2009). Of particular importance are fragmented healthcare systems where care is spread out across different systems and is disbursed by several poorly coordinated providers (Agha et al., 2017) within fragile contexts where countries are typically subjected to severe shocks to the system including violence and conflict,

political instability, poor governance, severe poverty, refugee crises and even natural disasters (Hill et al., 2014). These situations present additional organizational challenges in terms of delivery of health services (Cebul et al., 2008; Fadi Abou-Mrad & Tarabey, 2014; Stange, 2009).

Indeed, socio-economic determinants of health have been placed at the core of the public health discourse and therefore, need to be taken into account when analyzing healthcare services (Lombrail, 2013, 2014; Lombrail & Pascal, 2005). In contrast, and to counter the fact that most of the research on organ donation and transplantation stems from higher income Western countries with relatively high rates of donation primarily from deceased donors (Ballesté et al., 2021; Vanholder et al., 2021), this thesis focuses on more fragile and fragmented contexts to address a second gap in knowledge. For example, in most of the Middle East and North Africa (MENA) region, in countries like Lebanon the rate of organ donation from live donors supersedes that from deceased donors. This is just one of the particularities of organ donation and transplantation in that region but it is important as it stems from the values and cultural beliefs of the populations addressed (Ballesté et al., 2021). Moreover, with few exceptions, Western countries enjoy a political and economic stability that allows them to engage with and develop more performant organ donation and transplantation systems. That is not the case for most countries of the Global South which like Lebanon face extreme fragility, political and economic instability, scarcity of resources and a fragmented healthcare system which despite the reforms of the 90s remains primarily privately run, publically funded and heavily contingent on the political agendas of the Ministers of Health.

Moreover, collaborative governance arrangements adopted by the Lebanese Ministry of Public Health (MoPH) to counter the lack of human resources and expertise adds another layer of complexity to an already difficult situation. In fact, this propels the Lebanese organ donation and transplantation model into the realm of collaboration and interorganizational controls which is a third gap that will be addressed in this thesis. All of these factors combined make the Lebanese case ideal for an in-depth analysis of the performance management of a Public Private Partnership (PPP) - based organ donation and transplantation system in a fragile and fragmented healthcare context. Hence this doctoral thesis proposes to dwell on the general research question: "What performance management model can be proposed for an organ donation and transplantation system in a fragmented and fragile healthcare context?". In order to answer this question, the thesis will be guided by the following four research questions:

- 1. How can the performance of an organ donation and transplantation system be defined?
- 2. What performance issues can be identified in an organ donation and transplantation system in a fragmented and fragile healthcare context?
- 3. How can a PPP-based governance and regulation solution to the performance management issues of organ donation and transplantation be analyzed?
- 4. What could be the contribution of interorganizational control literature to address PPP-based governance and regulation issues for organ donation and transplantation?

This research is underpinned by an interpretivist worldview that drives the creation of knowledge by constructing the process of organ donation and transplantation based on a qualitative case study design (Ryan, 2018). The latter allows the exploration of the management of organ donation and transplantation through the functioning of particular governance and regulatory mechanisms within a specific healthcare setting. The case study research design (Yin, 2014) focused on a single case namely, the management of the Lebanese process of organ donation and transplantation but the thinking process and development of method of analysis was supported by a case series review of the process of organ donation and transplantation in the United States, Spain, France and Turkey. Semi-structured interviews were conducted with members of the National Organization for Organ and Tissue Donation and Transplantation in Lebanon (NOD-Lb) and the MoPH in order to get a holistic picture of their roles, the hierarchy and functioning of NOD-Lb as well as the characteristics of its collaboration with the MoPH. The interviews were then transcribed and analyzed for recurring themes using a thematic analysis. The validity of the results was ensured through member checking and the triangulation of data (Creswell & Creswell, 2017; Noble & Smith, 2015; Whittemore et al., 2001). The rigor of the study was further secured through the reflexivity of the researcher, maintaining an audit trail and providing thick descriptions and verbatim accounts to support findings.

As evident by the highlighted gaps and the proposed research questions, this thesis intends to add to the literature that addresses the issue of organ shortage as an economic problem in need of performance management, governance, collaboration and

regulation. Following a NPG perspective and the use of a value-based model (Bao et al., 2013) the thesis will contribute to public health governance, performance management and interorganizational control literatures by analyzing the performance management of a public private partnership based governance model in a fragmented healthcare context.

The thesis is organized in three parts and divided into six chapters preceded by an introductory chapter and followed by a concluding chapter. The introduction provides a general overview of the thesis that introduces the research problem, the context in which it will be analyzed as well as the theoretical and methodological considerations that will be addressed and exploited throughout the thesis. Part I positions organ donation and transplantation within a performance management. Chapter 1 summarizes the organ donation and transplantation literature emphasizing the gap in terms of performance management. Chapter 2 develops the research context, namely the fragmented Lebanese healthcare system, and describes the research strategy that is adopted in this thesis. Part II focuses on the organizational challenges of performance management in organ donation and transplantation systems in an emblematic case of fragmentation and fragility. This part is divided into two chapters. Chapter 3 presents a structured review of different models of organ donation and transplantation from a performance management perspective while chapter 4 consists of an in-depth case study of the organ donation and transplantation system in Lebanon, a fragmented healthcare system in a fragile context, focusing on governance issues. Part III delves into the characteristics of and issues with a PPP-based performance management

model. This part is divided into two chapters: chapter 5 which investigates the use of a PPP as a governance and regulation model and chapter 6 which revisits PPP-based governance and regulation from an interorganizational control perspective. Finally, the thesis concludes with a chapter that focuses on the contributions, implications and limitations of the thesis as well as future research perspectives. The thesis structure is summarized in figure 1.

Public private partnership-based performance management in fragmented healthcare systems:

the case of organ donation and transplantation in Lebanon

Introduction		
Part I: Positioning organ donation and transplantation within a performance management perspective	Part II: Organizational challenges of performance management in organ donation and transplantation systems in an emblematic case of fragmentation and fragility	Part III: A PPP-based performance management model for organ donation and transplantation in a fragmented healthcare system within a fragile setting
<ul> <li>Chapter 1: Organ donation and transplantation in the era of new public governance: a research issue</li> <li>Chapter 2: Lebanon, a fragmented healthcare system in a fragile setting: the research context</li> </ul>	<ul> <li>Chapter 3: A structured review of the problems faced by organ donation and transplantation models: a performance management perspective.</li> <li>Chapter 4: The Lebanese system of organ donation and transplantation: an analysis of the governance issues</li> </ul>	<ul> <li>Chapter 5: Analyzing PPP-based regulation and governance models</li> <li>Chapter 6: PPP-based governance issues revisited in the light of inter-organizational control</li> </ul>
Conclusion		

Figure 1: Thesis structure

Source: author's compilation

# PART I: POSITIONING ORGAN DONATION AND TRANSPLANTATION WITHIN A PERFORMANCE MANAGEMENT PERSPECTIVE

The objective of Part I is to demonstrate the paucity of research addressing organ donation and transplantation from a performance management perspective compared to the ethical and/or marketing ones and underscore the interest of analyzing organ donation and transplantation systems from this angle.

Inspired by NPG doctrines and a value-based model that highlights the importance of governance and performance management in the delivery of a public good, this part proposes health governance, analyzed using Mikkelson-Lopez's (2011) health governance framework, as a key concept in health system performance. This part also suggests adopting Ferreira and Otley's (2009) performance management systems framework to bring forward performance management issues in organ donation and transplantation systems. Furthermore, emphasizing the challenges of healthcare delivery in fragmented healthcare systems in fragile settings, highlights the importance of analyzing performance management in a fragmented healthcare system in a fragile setting using the case of Lebanon as an emblematic case.

This part consists of two chapters. Chapter 1 presents a review of the literature on organ donation and transplantation and highlights the paucity of scholarly articles

addressing the organ donation and transplantation process from a performance management perspective. The chapter continues to define concepts of public health governance and performance management and proposes the frameworks that could be mobilized to enhance the study of organ donation and transplantation issues.

Chapter 2 describes the research context and strategy that will drive the thesis. The chapter begins with a definition of the concepts of fragility and fragmentation, showing how they could act as potential issues for performance management. The chapter then describes the characteristics of the healthcare system in Lebanon. The chapter ends with a presentation of the research questions and a development of the methodology that will be adopted throughout the study.

## CHAPTER 1: ORGAN DONATION AND TRANSPLANTATION IN THE ERA OF NEW PUBLIC GOVERNANCE: A RESEARCH ISSUE

This chapter which serves as a foundation for the thesis is divided into two sections. This first section provides a general overview of organ donation and transplantation worldwide by presenting issues raised by the global problem of organ donation and transplantation and summarizing the available literature on the topic from an ethical and marketing as well as a management/organizational perspective. This section puts forth the possibility of addressing organ donation and transplantation as a complex process that can be scrutinized using a performance management lens.

Section 2 of this chapter exploits the New Public Governance literature and its emphasis on value-based frameworks to introduce and link the concepts of public health governance and performance management. The section concludes by highlighting their potential role in understanding challenges with the organ donation and transplantation process and offering potential solutions as analyzed from this angle.

#### 1.1. ORGAN DONATION AND TRANSPLANTATION WORLDWIDE

Transplantation is recognized as one of the most important medico-surgical accomplishments of the 20<sup>th</sup> century (Karamehic et al., 2008) and in fact, it has been suggested that it could potentially prevent more than 30% of all deaths in the United States (Giwa et al., 2017). Advancements in surgical procedures, the development of effective immunosuppressive drugs and the progress in organ preservation techniques have provided the means for the growth of organ transplantation with its capacity to

save and improve the quality of life of patients with end-stage organ failure (Black et al., 2018; Burra et al., 2007; Galasiński & Sque, 2016; Girlanda, 2016). This makes the paucity of organs one of the major public health challenges of the century and put forward the question: How are different countries worldwide addressing the scarcity of organs?

#### 1.1.1. Organ donation and transplantation - the global situation

Organ recipients today have good survival prognosis and improved quality of life indicators (Rana & Godfrey, 2019; Vanholder et al., 2021). In the United States, the chances of survival for kidney transplant beneficiaries relative to patients on the waiting list doubles after deceased donation and quadruples after living donation with a median survival time of 12.4 years (Rana & Godfrey, 2019). Around 50% of liver and heart recipients have more than 7-year survival rates with median survival in adult populations of 11.1 years for the liver and 9.4 years for the heart. Survival rates are even higher in pediatric populations. Long-term survival rates for primary kidney transplants from both deceased and living donors are even higher in Europe, Australia and Canada with 5-year survival rates of 79% and 87%, 81% and 90%, and 81% and 91% respectively (Hariharan et al., 2021).

Furthermore, although the economic impact of organ transplantation is difficult to assess, there is evidence that these operations are cost effective to the extent that they reduce the burden incurred by the continuous need for consultations, medication, surgery, imaging, interventions and hospitalizations associated with chronic organ

failure (Vanholder et al., 2021). For example, findings from a study in Canada suggest that kidney transplants incurred an average saving in cost of annual healthcare per patient of 24% to 29% when compared with the annual costs of care before the transplant (Koto et al., 2022). Moreover, patients with these diseases might have periods of interrupted employment and need to purchase medications as well as manage hospital visits, diet restrictions and multiple comorbidities, all of which add to the financial burden of their illness.

Organ donation is possible from both deceased and living donors and one donor has the potential to save up to eight lives with the possibility of donating both kidneys and lungs as well as the heart, liver, pancreas and small bowel (Furlow, 2012). Globally, according to the latest figures of the Global Observatory on Donation and Transplantation (GODT), in 2019, 17.5 transplants per hour were performed with a total of 153,863 organs transplanted in that year (*Global Observatory on Donation and Transplantation*, n.d.)). This constitutes a 4.8% increase compared to 2018. Yet, the number of organs transplanted worldwide is less than 10% of what is actually needed and this shortage in organs remains one of the major public health challenges nowadays (Giwa et al., 2017).

In fact, in the United States of America (USA) alone, there were more than 109,000 individuals on the national transplant waiting list at the end of September 2020 with a person being added to that list every 9 minutes ("Organ Donation Statistics | Organ Donor," n.d). Figure 1.1 describes the discrepancy between the supply and demand of

organs in the USA over time with the number of individuals waiting for an organ being more than five times that of the number of donors available and transplantations performed.

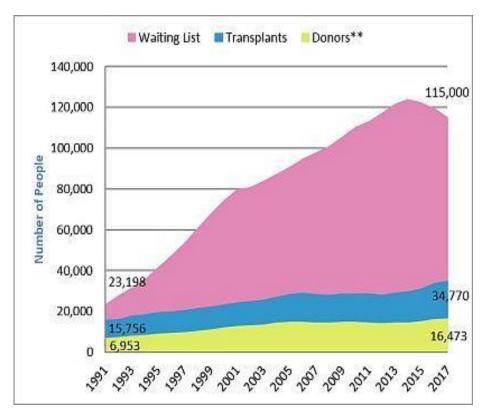


Figure 1.1: Number of people on the national waiting list per year in the USA

Source: Data from optn.transplant.hrsa.gov and OPTN/SRTR

Similar statistics are available for other countries. In Canada, for example, there are more than 4,500 people waiting for an organ with around 1,600 added to the organ transplant waiting list each year and an average waiting time for a kidney of four years (*Transplantation Statistics*, n.d.). In the United Kingdom (UK), 4,813 transplants were performed in 2019 and there were 5685 people on the active transplant list waiting for

organs as on March 31, 2020 ("Statistics about organ donation," n.d). By the end of 2018, there were 14,129 patients on the active waiting list of all the eurotransplant member states (Austria, Belgium, Croatia, Germany, Hungary, Luxembourg, the Netherlands and Slovenia) with 10,443 new registrations on the waiting list in 2018 (*Eurotransplant - Statistics*, n.d.). In the Scandinavian countries in that same year, there were 1950 transplanted patients, 1910 active for transplantation and 129 died on the waiting list (*Welcome to Scandiatransplant — Site*, n.d.).

### 1.1.2. Organ donation and transplantation - an ethical and marketing perspective

The literature on organ donation and transplantation is rich in studies investigating a variety of approaches to improve both living donation and deceased organ procurement (Ladin et al., 2015; Manyalich et al., 2013; Rudge et al., 2012; Saidi & Hejazii Kenari, 2014). Such measures focused on expanding live donation by using organs from both living related and unrelated individuals, maintaining a national effort to develop deceased donor donation, promoting split organ donation and paired donor exchange, as well as elaborating national sharing models and encouraging the use of expanded criteria donors (Saidi & Hejazii Kenari, 2014). Efforts included formulating or reformulating legislature (Coppen et al., 2010; M. J. Weiss et al., 2020, 2021; M. J. Weiss & Dirk, 2021), increasing public awareness, developing standardized donor management protocols as well as analyzing several factors believed to be associated with rates of organ donation, procurement and transplantation (Ladin et al., 2015; Quick et al., 2016). The latter consisted mostly of educational interventions for health

professionals, social awareness of the general public, religious and ethical considerations, legislative modifications, financial incentives as well as opting in/out modes and parental consent for deceased procurement (Krupic et al., 2017; Randhawa et al., 2012; Siminoff & Traino, 2009; Tong et al., 2013; Wong, 2010).

An abundance of research exists on the ethical concerns associated with organ donation and transplantation with a focus on tackling legislature, targeting religious leaders and engaging in a philosophical discourse about altruism and the act of giving as well as health inequalities that arise with the concepts of organ selling and trafficking (Bilgel, 2011; Chan, 2020; Modra & Hilton, 2015; Rutty, 2016). Similarly, from a marketing perspective, increasing public awareness, consent rates and health professionals' willingness to promote and engage in organ donation have been consistently studied in an attempt to increase the donor pool and as a result transplantation rates (Siminoff & Traino, 2009; Soyama & Eguchi, 2016). It was long considered that one of the main proponents of deceased organ donation was the optout as opposed to the opt-in configuration, where citizens would be assumed donors unless they specifically stated the opposite (Ahmad & Iftikhar, 2016; Arshad et al., 2019; Bea, 2021; Findlater & Thomson, 2015; M. J. Weiss & Dirk, 2021). Since the family of the deceased would have to make the ultimate decision, research has also focused on promoting methods for honest discussions between donors and the family members as well as procedures for increasing parental consent after death (de Groot et al., 2015; dos Santos & Feito, 2018; Findlater & Thomson, 2015; Laughlin et al., 2021; Marck et al., 2016; Ralph et al., 2014). Moreover, others investigated how the characteristics of

donors and attitudes of health professionals play a role in the donation process and analyzed the impact that knowledge and interventions to supplement it have on the intention to donate (Jawoniyi et al., 2018; Mercado-Martínez et al., 2013; Vargas et al., 2017; J. Weiss et al., 2014; Wong, 2010).

Studies attempting to evaluate the deficiencies in the process have focused mostly on deceased donor potential (Goldberg et al., 2017), conversion rates (Wynn & Alexander, 2011), consent rates (Koh et al., 2007) and the number of donors gained or lost at each phase (Domínguez-Gil et al., 2011; Graham et al., 2009). Although the successful application of organ donation and transplantation models has built in quality assurance programs, they still depend mostly on numeric information and statistics (Matesanz, Domínguez-Gil, Coll, Rosa, & Marazuela, 2011). Even in the action plan on organ donation and transplantation set forth by the European Commission (Farrell, 2010), five out of the ten priority actions address the challenge of increasing organ availability and as a result the attempt at governance in organ donation and transplantation from the European Union (EU) is mainly measured in terms of a successful decrease in organ shortage of the Member States.

Despite the recent contributions of qualitative research to transplantation practice and policy (Abt et al., 2013; Sarti et al., 2018; Tong et al., 2013), little has been done to actually follow the process on the ground, to explore the chain of events that start with the identification of a potential donor and lead to the actual transplantation of donated

organs in an attempt to identify potential problems in the flow of organs from the beginning of the chain to its end.

#### 1.1.3. Organ donation and transplantation - a process

Organ donation and transplantation depends on the accumulation of a series of embedded, institutional sub-processes and the improvement of the whole depends on an understanding and coordination of the parts (Manzano & Pawson, 2014; Miranda, Lucas, et al., 1999). In fact, the progression from the identification of a possible organ donor to the successful transplantation of a viable organ is a highly complex process that entails a series of different steps that cannot develop in isolation. Rather, organ donation and transplantation involve collaboration efforts among the different parts of the chain that links the beginning to the end. Indeed, it requires careful coordination of many, often geographically distant multidisciplinary teams. As an example, a typical deceased organ donation and transplantation process is detailed in figure 1.2.

It is clear from figure 1.2 how each stage in the evolution of the process is intrinsically dependent on the previous one and how any break in the chain might lead to failure.

Opportunities for maximizing organ donation therefore, occur at every step of the procurement pathway (Sharif, 2017).

In addition, organ transplantation, as opposed to other medical services, does not depend on medical expertise alone but rather has to take into account a series of important factors that are difficult to predict and control (Delmonico et al., 2011). These include, among others, the medical suitability of donors and recipients and the

willingness of live donors or deceased donors' families to donate. Hence, in order to ensure patient's interests, manage health professional's activities and respond to society's demands and expectations in a fair and ethical way, the organ donation and transplantation process definitely requires competent and structured management of the various interactions and complicated decisions involved at every step. Finally, the development of an efficient organ donation and transplantation system is an essential component to achieve self-sufficiency in terms of donor availability as well as organ recovery and exploitation (Matesanz, Domínguez-Gil, et al., 2011).

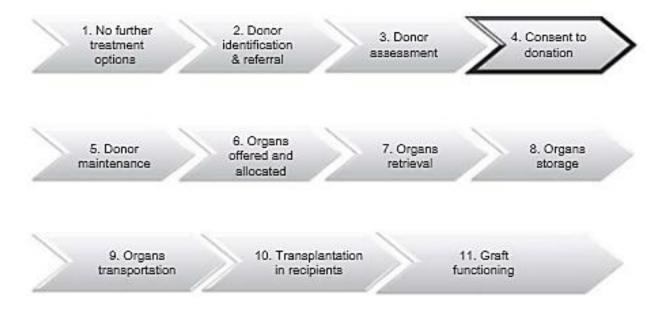


Figure 1.2: The process of deceased transplantation

Source: Manzano & Pawson, 2014

The majority of countries involved in solid organ transplantation have a national database of patients awaiting transplantation and well-established networks of organ retrieval and transplant specialist teams (Fleming & Thomson, 2018). It has been

postulated that the process of organ donation and transplantation can be evaluated from a system's perspective by considering that it is a complex adaptive system that continuously faces the challenge of matching supply to demand under the constraints of time and resources (Manzano & Pawson, 2014). The process of obtaining organs for transplantation is multifaceted as it involves different components, some of which are intrinsic to the hospital organization and performance while others have more macroeconomic dimensions that relate to the organizational and legal aspects of the country (Mizraji et al., 2014).

1.1.4. Organ donation and transplantation – a performance management lens
In contrast to the existing literature on organ donation and transplantation from an
ethical and marketing perspective, few studies have expanded on ways of improving the
efficiency of the organ donation and transplantation process (Graham et al., 2009)
through analyzing the management and organization of deceased organ recovery
programs (Freire et al., 2015; D. H. Howard et al., 2007; Marck et al., 2016; MercadoMartínez et al., 2013; Razdan et al., 2015; Siminoff & Traino, 2009). Some researchers
have endeavored to study the reliability of the process while attempting to identify
barriers to success and highlighting the challenges faced as well as possible
breakdowns in the links and potential problems of coordination and collaboration.
Quantitative studies concerned with process have faced issues of generalization as the
number of hospitals surveyed was limited and most of the problems identified were
contextual and dependent on the specific situation that they were in. A retrospective
study on decedents in the Western Pennsylvania and West Virginia organ procurement

organization (OPO) in the United States, found that controlling for potential confounders, it was four times more likely that an eligible decedent becomes an organ donor if there is no process breakdown such as missed or untimely referrals, suboptimal request for donation, de-escalation of care or early extubation (adjusted OR: 4.01; 95% CI: 1.6838, 9.6414; p < 0.01) (Razdan et al., 2015). However, process breakdowns do not seem to affect the number of organs yielded once the decedent becomes a donor. This study was done using data from one OPO only which resulted in the lack of generalization especially since there might be variations in recording from one OPO to the next as well as the potential of recall bias, contingent on the outcome. Another study looking at collaboration through a controlled pre/post design compared donation rates in 95 hospitals that participated in a quality improvement initiative that focused on identifying potential donors and obtaining consent for deceased organ donation to 125 control hospitals who did not participate (D. H. Howard et al., 2007). The findings show that conversion rates in the control group remained the same while they increased by 8% (p < 0.001) in the intervention group. Although this study adds to the growing body of literature on quality improvement efforts in health care, there were differences in the intervention and control hospitals and the study had issues with the internal and external validity of the results. A longitudinal study in six hospitals in Natal, Brazil investigated the association between structure (the organizational structure as well as the availability of physical, material and human resources), process (the step by step evolution including identification, notification, evaluation, maintenance, brain death diagnosis, family consent and documentation) and outcome (the actual donation of at least one organ) (Freire et al., 2015). Findings of this study suggest that there are

significant differences in process between donor and non-donor individuals especially with respect to maintenance and brain death diagnosis. The authors found statistically significant differences between the two groups in body temperature (p<0.001), the performance of care for cardiovascular function (p=0.047), renal function (p=0.011) and corneas (p=0.007), as well as the performance of neurological (p=0.002) and additional examinations (p=0.006). This study however, failed to examine the underlying reasons behind these results, an endeavor which was beyond the scope of the study.

In an attempt to tackle the same issue but from a different angle, a qualitative study explored the experiences of twelve donation coordinators in Mexico and highlighted the existence of a multitude of obstacles at various levels that had the potential to negatively affect the outcome of the process (Mercado-Martínez et al., 2013). These included factors at the structural, relational, and the ideational level. Donor coordinators identified problems such as the fragmentation of the health system, the scarcity of financial and material resources, non-egalitarian relationships between coordinators and hospital personnel and frequently associating deceased organ donation with death, failure and legal problems. This study although the first of its kind in Mexico and Latin America focused on the coordinators' perceptions but failed to explore actual practice or the perceptions of other health personnel involved in the organ donation and transplantation process. Similarly, a qualitative study among donors in Melbourne, Australia that focused on donor families' experiences with the organ donation and transplantation process highlighted the importance of direct and honest communication, difficulties with the formalities of the consent process, trust in and respect for healthcare

professionals, stress due to waiting time to donation and disappointment when the donation did not happen (Marck et al., 2016). Although this study included donors from various socioeconomic backgrounds, they were unable to approach non-English speaking families. Another limitation of this study was that due to the large number of staff involved their individual contributions and the influence of their training could not be assessed. A mixed study that consisted of a Rapid Assessment of Hospital Procurement Barriers in Donation conducted in 17 hospitals of a Northeastern OPO in the United States tackled the barriers to donation from the perspectives of hospital administrators, health care providers and staff through both individual and focus group interviews (Siminoff & Traino, 2009). The study highlighted deficiencies in the respondents' knowledge of organ donation, brain death and referral criteria as well a reluctance to declare brain death and problems of collaboration between the hospitals and the OPO. This preliminary evaluation led to the development of an intervention which resulted in improvements in the hospital's environment for organ donation in 9 out of the 17 hospitals. Although this study gathered information from the perspective of various participants in the process, it was based on only one OPO and its main focus was on the intervention and the assessment of its effectiveness. Since the OPO in question underwent organizational restructuring at the time of the intervention, there are concerns as to the adherence of the hospitals to the intervention and its recommendations.

Looking at the process of organ donation and transplantation from a system's perspective, Manzano and Pawson (2014), provided an initial framework for evaluating

the effectiveness of transplant coordination based on a program theory evaluation strategy. This model focused on the process within the hospital, ignoring pre-existing public attitudes to donation and prior social marketing efforts to influence them. Findings suggested that deceased organ donation depends on the accumulation of a series of embedded, institutional sub-processes and that the improvement of the whole depends on an understanding and the coordination of the parts. Another study by Dhakate and Joshi (2020) also explored organ donation and transplantation in India from a systems perspective by using Situation-Actor-Process and Learning-Action-Performance inquiry models to understand the complexities and interactions between the situation, the actors and the processes affecting organ donation and transplantation at the policy formation levels (Dhakate & Joshi, 2020). Findings highlighted potential process improvements through the identification non-value-adding (waiting and inappropriate processing) and value-adding (training of coordinators and raising family awareness) activities.

A report comparing organ donation and transplantation rates across Europe highlighted the potential of organizational changes in increasing donation rates (Tiessen et al., 2008). In addition, a systematic review identified, based on forty-one studies, elements that clearly highlight the central role of organization in the organ donation and transplantation continuum from government to hospital to citizens (Triassi et al., 2014). The government applied management strategies by taking a circular economy perspective that encouraged regeneration and de-componentization, while using an organizational toolbox that included structured networking, information sharing,

centralization and coordination. At the hospital level the organizational dimension was clearly expressed through organizational pathways and networking within, while the clinical and cultural barriers and beliefs remained organizational challenges from the societal perspective. Similarly, a study that reviewed the policies and clinical measures pertaining to organ donation and transplantation in several European countries, identified 12 key areas that might increase transplantation rates (Vanholder et al., 2021). These were divided into "approaches to advancing donation", infrastructural and collaborative approaches" and "other key areas" and although the first were ranked higher in importance, items such as equality, infrastructure, financing and benchmarking and evaluation audits were also included in the list.

Finally, most of the performance measures used to date serve to measure the efficiency of the system but do not address its complexity and multifactorial nature by analyzing relationships and organizational attitudes (Silva e Silva et al., 2021). A scoping review, attempting to define success factors for organ donation and transplantation, highlighted several process (quality improvement), structural (training/education) and contextual (public policies) factors including that contribute to the success of organ donation and transplantation. However, the investigators could not identify a single path to success as these factors were studied separately with no attempt to analyze the possible interactions between them that could impact on the success of the program.

#### 1.1.5. Organ donation and transplantation – gaps in the literature

In conclusion, understanding the performance of the organ donation and transplantation process is still in its infancy and efforts to date have mostly attributed its success or failure to the ethical and/or marketing aspects of donation (Manzano & Pawson, 2014; Mercado-Martínez et al., 2013; Razdan et al., 2015). The latter perspective has identified challenges such as lack of public awareness, understanding, fear and religious or cultural impediments as well as issues with presumed consent, financial incentives and healthcare personnel endorsement of the program. Moreover, although research has offered reliable statistics to evaluate the process, much less effort has been channeled into exploring the barriers to successful donation and identifying the breaks in the chain of events that link the beginning to the end of the process. In other words, efforts to date have concentrated more on performance measurement (Goldberg et al., 2017) than performance management with all that it entails in terms of interorganizational collaboration. Even less has been done from a governance perspective to acknowledge and evaluate the complexity of the collaboration between the private and public sectors in the regulation, management and provision of a national service (Ladin et al., 2015; Mizraji et al., 2014; Quick et al., 2016). With this angle in mind, it would be interesting at this stage to turn towards a review of the role of governance and performance management in the creation of public goods.

## 1.2. NEW PUBLIC GOVERNANCE: THE ROLE OF PERFORMANCE MANAGEMENT AND GOVERNANCE

With the emergence of the New Public Management (NPM) movement as a successor for the traditional public administration model, the past four decades have seen attempts to enforce private sector business principals to improve the performance of the public sector (Bao et al., 2013). Under NPM, doctrines are driven by the belief that government activity, policy-making and service delivery is based primarily on economic considerations and performance motivation with the assumption that human beings have individualistic tendencies and their behavior stems from instrumentality and individual rationality (O'Flynn, 2007). However, to date, researchers are far from reaching a consensus about the benefits of this movement in the improvement of public sector service delivery. On one hand, some scholars point to considerable advantages in terms of proactive problem solving, integrated systems and comprehensive measures of performance. Others, on the other hand, critique its focus on reform through market mechanisms and highlight, among others, its failures given the absence of a common comparator, the fragmentation of structures of authority and the political nature of the problems that need to be resolved (Angelé-Halgand & Garrot, 2014, 2015; Bao et al., 2013; Lapsley, 2009; McMullin, 2021; Osborne, 2006). Moreover, NPM is seen as context-specific and audience-dependent and describes a cluster of paradigms rather than just one. The dissatisfaction with NPM led to the rise of a new movement, NPG, that places the values that it aspires to meet at the center of the governance debate and focuses on mechanisms for building trust and legitimacy that are underrepresented in the NPM discourse (Bao et al., 2013; Bryson et al., 2014; McMullin, 2021; O'Flynn,

2007; Osborne, 2006). NPG emphasizes the creation of value through a co-production process that recognizes the importance of the collaboration between the public, the private and the non-profit sectors. Therefore, rather than limiting themselves to measuring effectiveness, efficiency and adequacy, proponents of NPG promote processes that facilitate the implementation of collective rather than individual preferences through the agreement of stakeholders with diverging views and opinions on the implementation of programs for the creation of a service for the good of all (Bao et al., 2013). Previous work in this domain points to the combination of governance and management skills in the development of the policy process and interorganizational relationships (Osborne, 2006) in an "era of governance through performance management" (Ferry & Scarparo, 2015, p.234). As a result, government performance is measured based on a holistic view of the system whereby all stakeholders work together towards the production of public goods and services. This perspective highlights the role of "history, social institutions, and culture in creating a shared system of values, agreement on governance processes and structures, and the respective roles that the private and nonprofit sectors play in the creation of the common good" (Bao et al., 2013, p.447).

This thesis exploits the value-based framework presented in figure 1.3 that emphasizes the importance of governance, management and leadership in the creation of public goods and the delivery of public services. A value-based model enables addressing the challenges and problems that governments face in the real world by taking into account the uniqueness of the contextual setting, the specificities of the problem to be solved and the alignment of political goals and local values (Bao et al., 2013). In the context of

this thesis, the public good would be providing for the organ donation and transplantation needs of the citizens and as explained in the previous section, this discourse has been lacking in the domain of organ donation and transplantation.

Although leadership is an important concept it is beyond the scope of this work which will focus essentially on governance and performance management. Therefore, the sections that follow will explore the definitions of both public health governance and performance management and propose a framework for the analysis of each concept respectively.

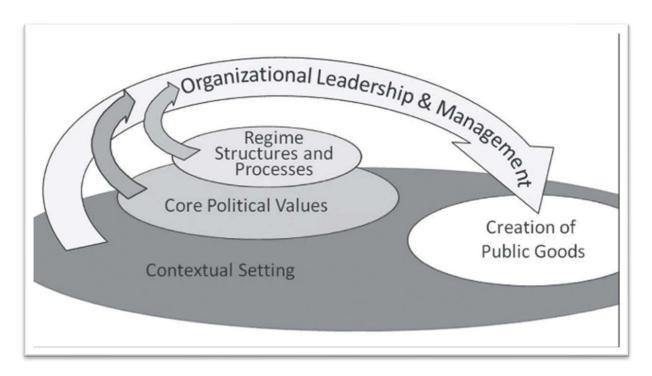


Figure 1.3: Structure and elements of value-based framework for performance management, governance, and leadership.

Source: Bao et al., 2013

#### 1.2.1. Public health governance: a key concept in health system performance

Governance is increasingly cited as a key factor in analyzing health system performance and balancing the concerns of the public and private sectors by acting as the main link between health departments and the communities that they serve (Barbazza & Tello, 2014; D. W. Brinkerhoff & Bossert, 2014; Carlson et al., 2015; Chanturidze & Obermann, 2016). Most theories and frameworks attempting to explain health system functioning have considered governance as a core element (Mikkelsen-Lopez et al., 2011; van Olmen et al., 2012). However, despite the interest in assessing health governance, the literature remains sparse (Siddiqi et al., 2009) and the notion remains poorly defined at both the conceptual and operational levels (D. W. Brinkerhoff & Bossert, 2014; Chanturidze & Obermann, 2016). One possible explanation for this could be the multitude of conceptual definitions and interpretations, often too broad and ambiguous, that have been attributed over time to governance in general and health governance in particular (Barbazza & Tello, 2014; Chanturidze & Obermann, 2016; Hufty, 2009; Saltman & Duran, 2015).

Traditionally, governance is defined as "the art of governing, the manner in which power is exercised by those who detain it" (Giraud-Roufast, 2013, p.6). In fact, leadership is often seen as the main driver of policy and changes are usually attributed to a particular figure such as a minister, public official, party leader or any person with the capability to influence politics or manipulate bureaucracies (Greer & Lillvis, 2014). However, health governance can no longer be characterized by this simplistic model that relies on the vertical authority of one leader but has to encompass the collective participation of all concerned stakeholders including the medical profession, the hospitals and health

technologies as well as the people in a continuous problem-solving endeavor (Giraud-Roufast, 2013; Greer & Lillvis, 2014).

Some authors still take a more focused view of governance by concentrating on a particular component such as accountability or specific functions (Barbazza & Tello, 2014). In general, most of the literature on governance and health has focused on single elements of governance such as degree of government effectiveness, degree of corruption and community participation (Mikkelsen-Lopez et al., 2011). According to D. W. Brinkerhoff and Bossert (2014), health sector governance has been mostly considered as tasks carried out in some form under the direction of health ministries (D. W. Brinkerhoff & Bossert, 2014). However, this conceptualization in terms of tasks and functions, does not take into account the multitude of actors involved in the process, the different roles that they must play and the responsibilities that they must embrace as well as their actual willingness to fulfill these roles and responsibilities (D. W. Brinkerhoff & Bossert, 2014; Vinot, 2014). Therefore, despite the broad range of interests and varying degrees of power that are inherent in the health system, it is nonetheless essential to address the two issues of coordination and durability (Greer & Lillvis, 2014).

In general, there is a consensus on health systems governance referring to the combination of processes, strategies and resources formally or informally applied to distribute responsibility or accountability among actors striving to promote and protect the health of their people (Barbazza & Tello, 2014; Hufty, 2009; Siddiqi et al., 2009). However, specific definitions vary. The main definitions used by international

organizations (table 1.1) namely, the European Commission, World Bank, UNDP, USAID and WHO are all framed in the context of the reduction of corruption and the increase of efficiency (Barbazza & Tello, 2014). In addition, various scholars have expanded on these definitions in an attempt to enhance them and adapt them more specifically to their context.

Chanturidze and Obermann (2016) have attempted to refine the WHO definition and advance that health governance is "the structures and processes by which the health system is regulated, directed and controlled" (Chanturidze & Obermann, 2016, p.508). Siddiqi et al. (2009) proposed, based on the UNDP definition, that "governance comprises the complex mechanisms, processes and institutions through which citizens and groups articulate their interests, mediate their differences and exercise their legal rights and obligations" (Siddiqi et al., 2009, p.14). Klakegg et al. (2008) put forward the Organization for Economic Co-operation and Development's (OECD) definition which suggests that public governance "refers to the formal and informal arrangements that determine how public decisions are made and how public actions are carried out, from the perspective of maintaining a country's constitutional values in the face of changing problems, actors and environments" (Klakegg et al., 2008, p.S28).

All these definitions although formulated differently share the concepts of interaction and collaboration among actors and agents with varying rights and responsibilities.

Given this ongoing debate on the concept of governance and the different definitions and interpretations put forth it is noteworthy to remember that governance processes

have characteristics that are based on cultural norms specific to certain societies in definite locations and as such cannot be generalized and transferred at will (Chanturidze & Obermann, 2016; Hufty, 2009; Ladin et al., 2015). With this in mind, perhaps a better definition of governance could be "the culturally appropriate rules, processes and institutions through which decisions are made and authority is exercised in order to achieve transparency, accountability, participation, integrity and capacity" (Chanturidze & Obermann, 2016, p.508).

In order to assess the impact of governance on health systems, researchers have proposed different operational definitions mostly based on methods of classification. As with the conceptual definition, the challenge remains to find the most appropriate operational definition (Chanturidze & Obermann, 2016). Governance can be divided according to (1) fundamental values such as control of corruption, democracy and human rights, (2) sub-functions including accountability, partnerships, regulation and transparency and (3) outcomes for example, effectiveness, efficiency, equity and improved health (Barbazza & Tello, 2014). Alternatively, it is also possible to focus on structure versus outcome (Chanturidze & Obermann, 2016). The concept could also be categorized using the different approaches to governance including: (1) governance as a synonym for government, (2) a normative governance framework, and (3) an analytical governance framework for nonhierarchical coordination systems which could consist of corporate governance, global governance or modern governance (Hufty, 2009). Moreover, as a result of these dilemmas, researchers in the field have attempted to develop theoretical frameworks for investigating these governance issues that incorporated the different facets inherent in the system thus moving beyond the existing mechanical health system representations (D. W. Brinkerhoff & Bossert, 2014; Hufty, 2009; Mikkelsen-Lopez et al., 2011; Saltman & Duran, 2015; van Olmen et al., 2012).

Table 1.1: Definitions of governance by international organizations

Organization	Governance Definition
European Commission (p.3) <sup>1</sup>	"The rules, processes, and behavior by which interests are articulated, resources are managed, and power is exercised in society."
World Bank (p.1) <sup>2</sup>	"The traditions and institutions by which authority in a country is exercised. This includes the process by which governments are selected, monitored and replaced; the capacity of the government to effectively formulate and implement sound policies; and the respect of citizens and the state for the institutions that govern economic and social interactions among them."
UNDP (Executive Summary) <sup>3</sup>	"The exercise of political, economic and administrative authority in the management of a country's affairs at all levels"
USAID (p.1) <sup>4</sup>	"The ability of government to develop an efficient, effective and accountable public management process that is open to participation and that strengthens rather than weakens a democratic system of government"
WHO (p.3) <sup>5</sup>	Leadership and governance "involve ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system-design and accountability"

Source: Barbazza & Tello, 2014

 $<sup>^{1}</sup>$  European Commission (2003). Governance and development. Brussels: Commission of the European Communities.

<sup>&</sup>lt;sup>2</sup> Kauffmann, D et al. (1999). *Governance matters*. Washington, DC: The World Bank.

<sup>&</sup>lt;sup>3</sup> UNDP. Governance for sustainable human development. (1997). United Nations Development Program.

<sup>&</sup>lt;sup>4</sup> Brinkerhoff, D. W., Bossert, T. (2008). Health governance: concepts, experiences, and programming options. United States Agency for International Development.

<sup>&</sup>lt;sup>5</sup> WHO. (2007). Everybody's business: strengthening health systems to improve health outcomes: WHO's framework for action. Geneva, Switzerland: World Health Organization.

Therefore, governance is fast emerging as a key component in the attainment of an efficient and effective health system that provides quality healthcare for all (Chanturidze & Obermann, 2016; Fryatt et al., 2017). It is clear that, although critical, strengthening health governance is a complex endeavor that strives towards upgrading quality, access and safety of health while catering to the multiple of conflicting demands and expectations of all concerned stakeholders (Saltman & Duran, 2015). However, it is essential to improving health and therefore, efforts should be invested in strengthening context-specific governance in low and middle-income countries (Fryatt et al., 2017). Once the concept of governance is clearly conceptualized and operationalized, frameworks can be proposed for its evaluation and used to inform policy debate (Chanturidze & Obermann, 2016; Fryatt et al., 2017). This thesis will focus on one such framework that will be adopted for the analysis of governance throughout.

In general, governance can be viewed as "the combination of political, social, economic and institutional factors that affect the behavior of organizations and individuals and influence their performance. It explicitly requires the identification of which organizations or individuals are the units of analysis and judges governance determinants against their impact. Fully characterizing any given governance determinant requires specifying the distribution of authority, the generation and use of information, and the ways actors are motivated" (Savedoff, 2011, p.15).

The framework proposed by Mikkelsen-Lopez et al. (2011) in figure 1.4, clearly demonstrates three main levels of the health system with service delivery in the center

surrounded by governance and eventually people or society. It is clear from this framework how other components of health system performance namely financing, medicines and technology, human resources, information that affect service delivery fall within the larger governance umbrella. It is therefore hypothesized that improving governance of the system in general should have a positive impact on improving the other dimensions of the health system and more importantly on service delivery. In fact, in a study that addressed public spending and outcomes, Rajkumar and Swaroop (2002) showed that increasing public spending had no impact when governance was poor (Rajkumar & Swaroop, 2002).

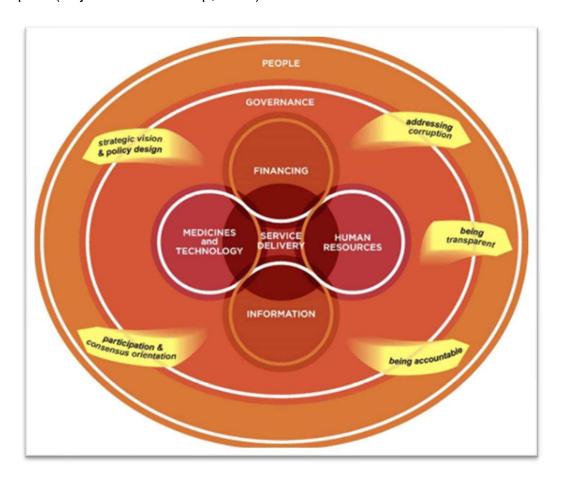


Figure 1.4: Assessing governance across the health system

Source: Mikkelsen-Lopez et al., 2011

This framework reinforces the findings of other researchers and highlights the significance of health governance. In fact, it would appear that before tackling each component of the healthcare system alone, it is important to start by focusing on governance and by conjunction, given the synergistic association mentioned in earlier sections, on performance management as a means to analyze and improve service delivery. In consequence, to complement the work developed this far, the next section will focus on defining performance management and providing a framework for analyzing it.

#### 1.2.2. Performance management in the public sector

The performance of an organization, defined as the manner in which an organization reaches its objectives, determines its success and continuity (Flapper et al., 1996; Marion et al., 2012). This necessitates that all of its members be on the same page and work together towards the same objective via their separate activities. Performance, therefore, requires measurement and management.

Performance management consists of a management style that allows tracking the performance of a system through well-defined performance indicators (PI) that can be measured and compared against success factors and preset targets that are achieved through planning and control (Flapper et al., 1996; Marion et al., 2012; Vignieri, 2018). It includes all activities, tools, and mechanisms that can be used to continuously measure and evaluate actual performance with the intent of improving it (Vignieri, 2018). This suggests that setting different PIs for a given organization should be done in a

coordinated manner with a holistic view towards the performance of the system as a whole rather than a task by task approach (Flapper et al., 1996; Marion et al., 2012). Whereas performance management is commonly used in human resource management as a means to control employee behavior, in the management, control and accounting literature it is seen to go beyond the measurement of performance to its management (Broadbent & Laughlin, 2009; Marion et al., 2012). Performance management systems therefore, "are concerned with defining, controlling and managing both the achievement of outcomes or ends as well as the means used to achieve these results at a societal and organizational, rather than individual, level" (Broadbent & Laughlin, 2009, p. 283).

The rise of the NPM movement has forced the public sector to reevaluate its focus and shift towards output control, outcomes and value production rather than action control, inputs, processes and enforcing compliance with administrative rules and procedures (Verbeeten, 2008; Vignieri, 2018). This led the public sector to look towards the private sector for new tools and technologies for measuring performance including benchmarking, balanced scorecard and lean management (Arnaboldi et al., 2015; Petit & Lux, 2020; Vignieri, 2018). However, the specificity and complexity of the public sector, requires the adaptation of the private sector tools and methods to particular environments and cultural values within organizations. Therefore, under the NPM hegemony and the common rhetoric of "more with less", the main challenge of public service managers as they strive to improve the quality of service delivery by maximizing the use of limited resources becomes in fact, performance management itself (Arnaboldi et al., 2015). More specifically, some studies have shown the benefits of the application

of performance management concepts in the private sector in terms of effectiveness of public services and impact for service users particularly where public acceptance of the performance indicators is high (Andrews, 2014; Ljungholm, 2015). In contrast, others have shown that the additional bureaucracy, routine procedures, lack of creativity, a concerted focus on goals and a fixation with measurement may affect the public servant's motivation and as a result lead to a decrease in performance (Arnaboldi et al., 2015; Verbeeten, 2008). Moreover, the effectiveness of public management is influenced by other factors including organizational culture and leadership (Andrews, 2014) and dysfunctionalities associated with inadequate political and managerial focus and a risk of tampering with measurement and reporting (Vignieri, 2018). This makes it essential to balance managerial values, with political priorities and institutional settings.

Performance is a multidimensional concept (Lux, 2017) and its management consists of a long-term strategy of a cyclical nature that takes into account the complexity of the value link and the approaches to achieve it (Vignieri, 2018). The model should be a sustainable one that can be applied year after year by improving the outputs that will become valuable inputs for the next cycle. Performance management is also interactive as it takes into account the view of all stakeholder in defining and performance indicators and promotes the sharing of results (Radu-Alexandru & Mihaela, 2019; Vignieri, 2018).

From a managerial perspective, performance management offers the advantage of clearly formulated missions, objectives and targets that can help employees stay focused, promotes transparency and accountability and provides learning and improvement opportunities (Verbeeten, 2008). The fact that performance management can be used as a basis for compensation, might also serve to ensure the quality and continuity of public service. However, given the diversity of countries around the world and the variations in the scope and features of the public sector, it is difficult to propose a single solution for performance management that takes into account the detail of different systems which are complicated by the specificities of their economic, political, external interference and demand for services contexts (Arnaboldi et al., 2015).

In an attempt to respond to the need for a more comprehensive approach to performance management that encompasses all the dimension of managerial activity and given that there is no single ideal model for performance management as it is contingent on a series of contextual and cultural factors that cannot all be accounted for, the Performance Management Systems (PMSs) framework proposed by Ferreira & Otley (2009) serves to describe the characteristics of performance management in a specific context (Ferreira & Otley, 2009). The framework (figure 1.5) consists of 12 questions that comprehensively summarize the main features of performance management and the way it is used in a specific organizational context. Although not exhaustive, the 10 "what" and 2 "how" questions form a coherent framework that serves as a useful tool to structure enquiry in this field by offering considerable insight into the different facets of PMSs design and practice. The contextual factors and organizational culture are considered contingent variables rather than inherent characteristics of the control system. They are used to explain differences in the effectiveness of certain

control patterns and are therefore not included in the framework. These factors include variables pertaining to the external environment, strategy, culture, organizational structure, size, technology, and ownership structure that need to be considered in order to make the analysis of performance management more complete. In fact, it is these contingency factors that vary from system to system that make it necessary to analyze organ donation and transplantation systems in various settings especially ones characterized by fragility, fragmentation, political and economic instability and multiplicity of the decision-making authority. These factors add a level of complexity to an already complex system that cannot be ignored and taking them into account will strengthen the analysis and enrich the conclusions.

Moreover, with the rise in the age of the populations and the healthcare costs applying performance management in the context of healthcare is tempting as it can offer solutions in an era of economic constraints (Petit & Lux, 2020). However, this task is even more complex in this particular sector given the continuous struggle between efficiency, control and values as well as the diversity of actors and roles involved in healthcare systems making it difficult to apply the same solutions across the board (Morinière & Georgescu, 2021), thus the added importance of contingency factors.

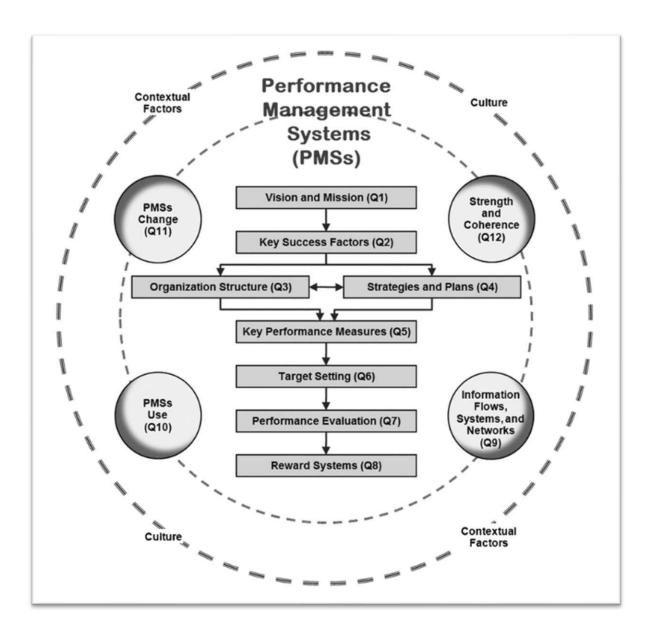


Figure 1.5: The performance management systems framework

Source: Ferreira & Otley, 2009

# 1.2.3. Governance, performance management and organ donation and transplantation systems – gaps in research

Applying the concepts of health governance and performance management to organ donation and transplantation models it is clear that they have not been properly

addressed in the study of organ donation and transplantation systems. In fact, although health governance is recognized as a crucial factor for the improvement of health delivery and has been at the center of health system's performance debates, its study is conspicuously absent from the field of organ donation and transplantation. Governance, accountability, authority and coordination have been linked to the organ donation and transplantation process (Delmonico et al., 2011), but few studies to date have approached organ donation and transplantation from a governance lens. The closest attempts include studies that tackled organ donation and transplantation from the perspective of culturally specific factors taking into account that it cannot be considered in a context devoid of all emotional, cultural, religious and political connotations (Lock & Crowley-Makota, 2008). These studies have expanded on determinants such as the human development index and its components (Mizraji et al., 2014), social capital (Ladin et al., 2015), social context (Lock & Crowley-Makota, 2008) and social interaction and reciprocity (Schweda et al., 2009). One success story comes from the state of Tamil in India where in 2008, the government initiated an organ-sharing network, the Cadaver Transplant program, that integrated all hospitals, government and private, NGOs, donors, recipients, police and social workers (Annadurai et al., 2015). This was one of the first examples of a successful collaborative arrangement in organ donation and transplantation.

As for performance management, although the concepts of performance its measurement and control have been introduced in the public healthcare sector (Angelé-Halgand & Garrot, 2014; Georgescu, 2013; Lux, 2017; Merle et al., 2009; Morinière &

Georgescu, 2021; Petit & Lux, 2020; Vinot, 2014), it has not been overly analyzed in the context of organ donation and transplantation. To the author's knowledge, the few studies that could be identified either focused on improving performance measurement of a particular indicator rather than management (Goldberg et al., 2017) or identified individual aspects of performance rather than taking a holistic approach (Silva e Silva et al., 2021; Vanholder et al., 2021).

This thesis intends to address these gaps in the literature by considering organ donation and transplantation a public service and focusing on its performance management using the PMSs framework, and in consequence governance, to understand their role in the provision of service delivery. Now that gaps in the organ donation and transplantation literature have been exposed and the theoretical background of public health governance and performance management have been exposed, the next chapter highlights the fragmentation and fragility of the Lebanese context justifying its use as a research context for analyzing performance management in a fragmented and fragile situation. The chapter ends by detailing the case study methodology that is the basis of this thesis.

# CHAPTER 2: LEBANON, A FRAGMENTED HEALTHCARE SYSTEM IN A FRAGILE SETTING: THE RESEARCH CONTEXT

This thesis aims to address the performance management of organ donation and transplantation in a fragmented healthcare system in a fragile setting. Fragmented health care, as the word suggests occurs when there are multiple decision-makers responsible for healthcare delivery at different levels (Elhauge, 2010). In other words, care is found spread out across different systems and is disbursed by several poorly coordinated providers (Agha et al., 2017). It is in fact a situation where each provider focusses on one part without having a comprehensive view of the whole (Stange, 2009). This can be very dangerous in a setting where the aim is to heal a person as a whole rather than concentrate on disjointed parts. Without a holistic understanding of the problem and full knowledge of the treatments received, it is possible that each subsequent treatment does more harm than good. This fragmentation lays the foundation for more obvious healthcare issues including cost increases, poor quality of care and inequality in service provision (Agha et al., 2017; Kaltenborn et al., 2021; Lombrail, 2016; Stange, 2009). Fragmentation in a healthcare system can occur at multiple levels as there could be fragmentation in costs and health insurance, fragmentation in hospital governance and care provision as well as fragmentation in organization and coordination (Lombrail, 2016). The availability of technology and a good information system could mitigate some of the problems that are associated with fragmentation such as inefficiency, ineffectiveness, inequality, commodization, commercialization, deprofessionalization, depersonalization, despair and discord (Stange, 2009). These problems are compounded in fragile contexts where countries

are typically subjected to severe shocks to the system including violence and conflict, political instability, poor governance, severe poverty, refugee crises and even natural disasters (Hill et al., 2014). In such situations, the public administrations find themselves incapable of providing essential services for their citizens, a position that negatively affects all state institutions (social, political, or economic) and particularly the health sector and access to essential services (Ramadan et al., 2021). The consequences of this fragility include a chaotic public health system characterized by unreliable service and disrupted access, a paucity of reliable evidence to inform policy and decision-making and the emergence of predominantly private, opportunistic healthcare networks (Hill et al., 2014). Moreover, this will increase the fragmentation of the health system, and will impact on the regulation of the pharmaceutical sector and the stability of the human workforce.

With these concepts in mind, this chapter presents the context of the research by describing in detail the Lebanese healthcare system and its fragmented service delivery. The chapter will also highlight the fragility of the political, administrative and economic context in which this fragmented healthcare system functions. The chapter also includes a description of the Lebanese society and the particularities of the Lebanese culture that in some ways feed the fragmentation and fragility of the situation even further. The chapter ends by exposing the research questions and developing the research strategy that was implemented throughout this work.

# 2.1. A FRAGMENTED HEALTHCARE SYSTEM IN A FRAGILE SETTING – THE CASE OF THE LEBANESE HEALTH SYSTEM

The Lebanese health system with its particular mix of private sector hegemony and public sector financing is an atypical system whose development is a prerequisite to establish effective, efficient and equitable services (Ammar, 2009; Ammar et al., 2016; IGSPS, 2012; Khalife et al., 2017). It is, in fact, best described as a fragmented and pluralistic system with service delivery predominantly ensured by a private sector whose resources, both human and material, are heavily dependent on public licensing and funding. In addition, the weak regulatory presence of the MoPH has encouraged opportunistic behaviors in both consumers and suppliers that has led to a health sector characterized by a surplus of beds and medium-sized well-equipped hospitals.

The Lebanese health sector is also characterized by an inter sectorality that has always been embedded in all health strategies and actions. When necessary, the MoPH coordinates and collaborates with various stakeholders including different ministries and governmental agencies, service providers, national and international funders, and engages with civil society, UN agencies, universities and research centers to respond to emerging needs.

The system as it exists today has been shaped by its historical development which can be divided into five phases namely, pre-independence (1864-1943), independence (1943-1960), reforms (1960-1975), the civil war (1975-1992), the present (1993-to

date). What follows is a brief overview of its development with an emphasis on the major influential events in each phase (Asmar, 2011).

#### 2.1.1. The development of the Lebanese health system

Medical practices started in Lebanon towards the middle of the 19<sup>th</sup> century, were concentrated in the big cities and depended on a few qualified physicians who were either part of the Ottoman army or affiliated to missionary organizations. The latter were also instrumental in the introduction of medical education and training into the country. During that time healthcare was in the realm of medical units set up by mostly religious, charitable organizations. Public hospitals were small and catered primarily to the poor population afflicted with contagious diseases. The role of the government consisted mainly in the protection of the its citizens from infectious diseases and environmental risks (Kronfol & Bashur, 1989).

After the first world war, the country was placed under French mandate and was therefore heavily influenced by the French system from which it borrowed the models of inspection, control and centralization. This period saw the establishment of the first Department of Health which was placed under the Ministry of Interior and the appearance of small private hospitals once again inspired by the French clinics that were available at the time.

With the declaration of independence, came the establishment of a Ministry of Health and Social Affairs whose principal responsibilities included the supervision, coordination

and legislation of health as well as the protection of the environment and the control of infectious diseases. In the 1950s the Ministry worked on developing a public health system that consisted of internal administrative structures and a small network of public hospitals and primary care centers intended to deliver free services to the needy. However, most of these institutions were centralized which made them inaccessible to a large proportion of the population. In parallel, the country experienced a boom in private hospitals that offered better quality services.

In 1958, the Lebanese government proposed several reforms that had a major impact on the health system. Of these the most important were the 1961 decree that put the Ministry of Health in charge of the health of the public especially the needy and the 1963 decrees that led to the creation of the National Social Security Fund (decree 13955) and the Civil Servants Cooperation (decree 14273). The first decree led to the development of a network of public and private primary healthcare centers meant to ensure the needs of the population. The second decree saw the creation of a semipublic institution with financial and administrative autonomy modeled according to the principles of the European social security as well as the establishment of a public organization under the leadership of the Council of Ministers.

Unfortunately, these reforms did not have the positive impact expected. On the contrary, they further weakened the role of the Ministry of Health in the public sector (Asmar, 2011; Kronfol & Bashur, 1989; Lerberghe et al., 2018) and created duplication of in terms of services and coverage provided. The fee-for-services reimbursement mode led

to over-prescription of medical consultations, laboratory exams and medications and the proliferation of governmental coverage mechanisms which opened the door to competition and political gain rather that coordination and collaboration.

In 1975, with the advent of the civil war, there was a deterioration in the services provided by the Ministry of Health which eventually ceased to function as the public sector collapsed. The solution came from the private hospitals with which the Ministry contracted out to ensure the healthcare needs of the population and the victims of war. The Ministry thus took on the role of the funder for these hospitals and acted as a contracting agent rather than a regulator of healthcare (Asmar, 2011; Kronfol & Bashur, 1989). This led to an increase in the expenses of the Ministry whereby 80% of the allocated budget went towards coverage of secondary and tertiary care (Ammar, 2009). The Ministry also provided costly medication to the population for free.

At the end of the war, the public health system was in shambles. The Ministry of Public Health was incapable of assuming its regulatory role and the public sector was paralyzed due to the destruction of most of its facilities. Healthcare delivery, therefore, became highly dependent on the private health sector which continued to grow, albeit chaotically. This resulted in a focus on curative care and the use of advanced technologies at the expense of preventive and primary health care. In addition, health coverage was not equitable as although the Ministry continued to cover the uninsured population, the National Social Security Fund found itself incapable of covering the fees of healthcare services due to the dire economic situation in the country. Private

insurances offered an outlet but only to a certain socio-economic level. Moreover, healthcare services were concentrated in big cities and urban centers which reduced accessibility in terms of both quantity and quality of services. Human resources were sadly lacking due to the massive brain drain of health professionals as well as the imbalance in their distribution and specialization (Ammar, 2009). Finally, in terms of health financing and expenditure, the fragmentation and compartmentalization that existed between the various public, semipublic and private funds in the country (Kronkfol, 2006) and the absence of effective control mechanisms resulted in weak purchasing power, high administrative costs and a policy that further encouraged activities aimed at increasing medical costs (Ammar, 2003). In addition, the continued escalation of costs places the country in terms of health expenditure at a level close to that of industrialized countries and therefore induces a heavy financial burden on household spending especially in the form of out-of-pocket expenditures.

Faced with this situation, the Lebanese Government adopted in 1993 a strategy for the rehabilitation of the health sector with as its main objective strengthening the regulatory role of the Ministry of Public Health and reducing health expenditure.

#### 2.1.2. A weak public health sector

The Lebanese public health sector is led by the Ministry of Public Health (MoPH) which is responsible for regulating the system, making all decisions and disseminating all information concerning the health of the Lebanese citizens. The MoPH is characterized

by both a centralized and decentralized administration which is divided into four geographically tiers namely, central, regional, area and local.

The centralization of the system is apparent at the level of the central tier which consists of the central administration of the MoPH and the referral public university hospital. The administrative structure of the Ministry where all regulatory, decision-making and dissemination activities are concentrated, is subdivided into three major directorates in charge of all curative medical care, preventive health care and the central laboratory. The medical care directorate consists of two units that oversee all activities related to hospitals, dispensaries, medical professions as well as pharmacies and pharmaceuticals. The preventive health directorate comprises four services namely social health, occupational health care, preventive medicine, and sanitary engineering as well as a department of health and biostatistics. Activities contained within this directorate include the primary health care centers network, the Universal Health Care project, the surveillance and response programs for communicable diseases and the cancer registry. The third directorate is currently closed.

The decentralization comes at the level of the other three tiers. At the regional level each governorate in the country has a public health service department affiliated to the MoPH that oversees regional healthcare activities such as the authorization of the MoPH subsidized hospitalization for patients with no coverage from any other public fund (Ammar, 2009). The district level consists of health departments served by one or

more functional secondary public hospital and finally the local tier is at the level of the municipalities with the primary health care centers and dispensaries.

Healthcare services which are provided through several public hospitals and a network of primary healthcare centers and dispensaries are distributed into primary, secondary, and tertiary care facilities with the first mostly located at the local level while the secondary care facilities are found at the district and regional levels and the tertiary care facilities are mainly at the central level. In addition, the uniformed forces have their own private facilities that allows the provision of healthcare provision to their beneficiaries and eligible relatives. However, due to the limited capacity of the public services, the MoPH regularly signs contracts with private hospitals for service provision and collaborates with several other sectors depending on the type of health program implemented.

Health services covered by the ministry are mainly secondary and tertiary delivered in public hospitals that provide free general care and are distributed all over the Lebanese territory. However, public hospitals in Lebanon are in general under-equipped, offer bad quality services and lack qualified professionals. Only one public hospital has the status of a university hospital, and most have less than 100 beds. Until 1996, these hospitals were managed like administrative units of the MoPH with centralized management and budget allocations that were based on estimations rather actual need. However, with the promulgation of the law of autonomy of public hospitals (law 544) which aimed at granting public hospitals more flexibility, they started operating as semi-autonomous

entities accountable to a Board of Administration appointed by the Council of Ministers.

This led to improvements in efficiency and encouraged competition between the private and public sectors, thus improving the quality of services offered in the public sector.

Primary care services are delivered based on a contractual agreement through a network of mostly private primary health care centers (*MoPH*, 2022), distributed across different Lebanese regions. The centers are committed to provide a package of basic health care services while MoPH provides technical support, such as reduced cost consultations, free distribution of prescribed chronic medications (cancer, HIV & psychotropics), as well as essential drugs and immunization. In addition, there are numerous dispensaries that cover vaccination especially polio, pentavalent & measles.

### 2.1.3. The domination of the private health sector

The private health sector which has been attracting investors since the post-war period, became the hub for political and entrepreneurship investments (Lerberghe et al., 2018). As the capacity of private hospitals increased along with the number of physicians, pharmaceutical companies and sophisticated equipment, the private sector became a key market player. As such, the private sector established a cooperation with the MoPH for service provision that had critical consequences on the national budget, as the debt owed by the MoPH exceeded the entire MoPH budget. Moreover, most private hospitals evolved in a free market with unregulated development which resulted in a considerable number of highly equipped and sophisticated hospitals and clinics, putting Lebanon, in terms of technology, at the same level as high-income countries.

There is no doubt that as the main provider of services for all beneficiaries whether covered by out-of-pocket payments, private insurances, public funds or through the private public partnership with the MoPH, the private sector plays an essential role in the healthcare landscape of the country. Therefore, the private health sector is the backbone of the Lebanese healthcare system and dominates healthcare delivery in Lebanon by providing at least 80% of the overall health services within both hospital and ambulatory care settings spread all over the territory. Private hospitals, mainly general multidisciplinary hospitals with 80 to 450 beds per hospital, provide secondary and tertiary inpatient care while a developed network of private health facilities offers lucrative ambulatory care. There are also around five hospitals that have been licensed by the state as university hospitals which offer competitive medical programs and health training.

The private health sector is regulated by the professional orders and syndicates.

Lebanon has two Orders of Physicians as well as separate Order of Nurses, Dentists and Pharmacists which regulate their respective professions and clearly define their missions and roles. Private hospitals are regulated by the Syndicate of Private Hospitals which was established by Ministerial decree 1/523 in 1965, as the official representative of all private hospitals.

The profit and expenditure of the private sector is mainly dependent on the contracts established with the MoPH, as 64% of the private hospital budget comes from public financing, with the MoPH providing around 30% of that budget.

#### 2.1.4. Civic society organizations and Initiatives

The civil society in Lebanon has always been very active and includes professional Orders, Syndicates as well as NGOs (Ammar, 2009). A wide network of health centers run by not-for-profit NGOs provides ambulatory primary health care services. NGOs also have intersectoral activities in health and social matters and have expanded greatly over the years to contribute to areas where the state could not due to lack of expertise or resources.

NGO activity started in Lebanon in the early 1900s and focused on providing social services primarily to the orphan and elderly populations. During the civil war, due to the devastating economic, social and political depression, NGOs started assuming the role of service providers using independently acquired funds from mostly international donors thus provided a safety for the vulnerable populations (Asmar, 2011; Lerberghe et al., 2018). It was not until 1996, that the MoPH recognized the efforts in service delivery and strong emergency response showcased by the NGOs and established the first MoPH-NGO collaboration for emergency response especially focused on the vulnerable populations. The support provided by the MoPH improved the quality of and access to care offered by the NGOs that embodied the social counterpart of the MoPH to provide assistance to the most impoverished sector of the population (Lerberghe et al., 2018).

### 2.1.5. Regulation of the health sector

All aspects of public health in Lebanon are covered by a legal framework for regulation and governance of health services (*Legiliban*, n.d.; *MoPH*, 2022). Most laws go back to the 1920s and have not been updated since. However, some application decrees were later issued to enhance the application of these laws. At the legislative level, the "parliamentary commission for health" is the body responsible for discussing and finalizing law projects and decrees related to health before submitting them for voting in the parliament.

As the private sector greatly depends on the public sector, the Ministry of Health has also sought to strengthen its leadership and governance functions through a national regulatory authority for health and biomedical technology, an accreditation system for all hospitals, and contracting with private hospitals for specific inpatient services at specified prices. It now has a database that it uses to monitor service provision in both public and private health facilities with the aim of achieving cost-containment, regulating private and public service delivery, encouraging frugality in the reliance on hospitalization, promoting quality of care and endorsing transparency (Lerberghe et al., 2018). The law of autonomy of public hospitals, the incentive-based regulation and the quality assurance programs set by the ministry, provided the appropriate market for a fair competitive and transparent system to access public subsidies.

The MoPH is also responsible for providing licensing, for all healthcare professionals seeking employment in Lebanon. In fact, to be authorized to practice privately on the Lebanese territory, all health professionals need to be registered in their respective

orders or syndicates and are required to pass the Colloquium Exam. However, the ministry does not control the quality of work of their work nor require any additional qualifications regarding medical professionals (IGSPS, 2012; Lerberghe et al., 2018).

#### 2.1.6. Financing of the health sector

In terms of health services coverage, Lebanon has a two-tier system which provides citizens with a basic essential health service package that is financed by a primary funding organism while complementary health services require the contribution of the beneficiaries (Ammar, 2003; Ammar et al., 2016; El-Jardali et al., 2012; IGSPS, 2012; Khalife et al., 2017). There are six employment based publicly managed funds subsidized through the governmental budget that cover 45% of the Lebanese population. These include the National Social Security Fund which serves the employees of the general regime, the Civil Servants Cooperative for civil servants, and four additional funds covering the Military and Security Forces. Additional coverage is provided by private insurances and Mutuality Funds. Each fund offers its beneficiaries a large range of basic services in ambulatory and hospital care. Each fund is under the tutelage of a different ministry and each ministry has its own regulations but with the exception of the NSSF which allocates funds through regional centers, all are centralized at the level of the general administration. The different public financing parties are submitted to accountability mechanisms by legislation from appropriate administrations such as The Lebanese Parliament, the Central Inspection Directorate and the Court of Auditors. As for the private insurance companies, they are registered

under the Ministry of Economy which regulates and oversees their function through a special commission (Ammar, 2003).

The remaining 55% of the population with no coverage are taken in charge by the MoPH who covers hospital care and limited ambulatory care services through a special allotment in its own budget on a single-payer basis. The MoPH therefore functions as the insurer of last resort by offering safety net to the citizens with no other recourse.

### 2.1.7. The role of collaborative governance

The civil war era in Lebanon saw the near collapse of the public health sector and the predominance of the private sector with most secondary and tertiary care services ensured by the private sector while primary care services were primarily covered by dispensaries affiliated to charitable or nongovernmental organizations (Lerberghe et al., 2018). In the years that followed, the health sector appeared to be dominated by powerful lobbies, characterized by political clientelism, dominated by a growing health sector and governed in principle by a weakened and marginalized MoPH that was still expected to subsidize health care despite the constrained budget already drained by years of conflict.

In an attempt to reposition itself as a key authority within the Lebanese health sector, to combat the fragmentation of the health system and the limited government resources, the MoPH developed its own model of collaborative governance which brought together public and private stakeholders in consensus-oriented networks that included partners

with shared goals and positive track records. Given the fact that the MoPH lacked the necessary expertise and means, collaborative governance was the only sound option at the time.

With this collaborative governance framework, the MoPH succeeded in replacing the laissez-faire attitude that dominated the sector at the end of the war and involving all stakeholders in the country in the elaboration and implementation of national health policies and strategies (Khalife et al., 2017; Lerberghe et al., 2018). Several key networks of collaboration with various forms of complexity and formalization were successfully built around sectoral priorities (Lerberghe et al., 2018).

Despite the many challenges that it faced due to both the political and economic situations, the fragmentation of the system, the large influx of refugees and the high lobbying environment in which it evolved, the emergence of the collaborative governance networks allowed the Lebanese MoPH to position itself as a key authority within the health sector. This collaborative governance initiative was accompanied by the application of a consensual leadership style and the transparent communication with the public and private stakeholders.

#### 2.1.8. The Lebanese health indicators

Until 2019, despite the challenges faced by the public health sector, Lebanon was considered a reference for healthcare in the region with large well-maintained private hospitals, a skilled workforce and the availability of advanced medical technologies

(Ammar et al., 2016). Moreover, the health indicators in the country were on par with those of the more developed countries.

Epidemiologically, Lebanon is in a phase of transition as the rates of infectious diseases decline while the rates of non-communicable diseases rise (Ammar, 2003, 2009; Asmar, 2011). In fact, non-communicable diseases account for 91% of all deaths in the country with 47% for cardiovascular diseases and 16% for cancers (*Lbn\_en.Pdf*, n.d.). In addition, one third of the population suffers from common risk factors for cardiovascular diseases including obesity, inactivity and smoking.

Between 2000 and 2015, Lebanon witnessed substantial improvements of its health indicators and managed to achieve the set targets for millennium development goals 4 and 5 related to child and maternal mortality (Ammar et al., 2016; *MoPH*, 2020) with a stable maternal mortality ratio at 13.4 per 100,000 live births and an infant mortality rate of 7.4 per 1000 live births in 2018 (Lebanese Ministry of Public Health, 2019). The crude death rate was 4.4 per 1000 population in 2019 (World Bank, 2021). Moreover, life expectancy at birth in 2019, was to 78.93 years which placed Lebanon in the same ballpark as European countries and at the top of the list among Arab states.

# 2.1.9. The Lebanese political and economic context of healthcare: An increasingly fragile context

Lebanon is a Middle Eastern country with an area of 10,452 km<sup>2</sup> located on the shores of the Mediterranean Sea which forms its Western border while Syria borders the

country from the North and East with Israel/Palestine forming the remaining border from the South. The country had an estimated population size of 6.86¹ million inhabitants in 2019 (World Bank, 2021), of which almost a third were refugees (*UNHCR-Lebanon-Operational-Fact-Sheet-January-2020.Pdf*, n.d.) making Lebanon the country with the highest number of refugees per capita and the 109th most populated country in the world (World Population Review, 2021). Approximately 89% of the population is found in urban areas and around a quarter (26%) are under 15 years of age while 7.3% are over 65 years (World Bank, 2021).

The Republic of Lebanon, whose independence was declared in 1943, is characterized by a Parliamentary democracy that is governed by the Lebanese Constitution and headed by a President who is elected by Parliament for a six-year term (Presidency of the Republic of Lebanon, n.d.). The Lebanese political system is based on the principle of checks and balances and the separation of the legislative, executive and judicial powers. The country is administratively divided into eight provinces (Mohafaza) and twenty-six districts (Qada) (Lebanese Arabic Institute, 2017). Districts are further subdivided into municipalities that enjoy a certain autonomy and administrative decentralization.

Economically, Lebanon is classified by the World Bank as an upper middle-income country (World Bank, 2021). The economic system is characterized by a free-market regime that favors entrepreneurship and private property. As a result, the private sector

<sup>&</sup>lt;sup>1</sup> The last census dates back to 1932. Currently available data are only estimates.

plays an important role in the Lebanese economy which is predominantly based on the tourism and banking industries that form around 70% of the country's national income. In 2019, the per capita gross domestic product (GDP) was estimated at 7,584 USD with a government expenditure of 29% and a trade balance that is traditionally in deficit as imports (61% of GDP) largely exceed exports (35% of GDP). The Human development index was 0.74 positioning the country as 92<sup>nd</sup> among 189 countries (United Nations Development Programme, n.d.).

#### 2.1.10. The Lebanese society and culture

This section describes characteristics of the Lebanese population as well as cultural influences that might shed light on the evolution of the Lebanese health sector and bear on the adoption of certain health-related attitudes and practices as well as directly or indirectly influence collaborative efforts.

The Lebanese population consists of a diversity of religions and sects that cohabitate together. Religion plays an important role in the governance of the country as most public positions including the president, members of parliament and ministers, are assigned in view of keeping the religious balance (Henley, 2016). In fact, proportional distribution among the different religious communities is generally respected in the parliamentary elections and the ministers and public administration nominations.

Moreover, civil affairs in the country such as marriage, divorce and inheritance are managed and regulated by respective religious authorities. As a result, religious leaders

occupy an important position in the society and play an influential role in all decisionmaking processes.

The Lebanese society is a patriarchal society that is traditionally conservative but open to Western influences and changes led by globalization and immigration. The family in its extended form plays a central role in all aspects. It is considered a source of both emotional and financial support and contributes to the individual's development. Indeed, it is common to find family members living in the same home or building and having weekly family reunions is the norm rather than the exception. Moreover, family businesses are a large part of the economic fabric of the country. Gender separation and the role of women is also contingent on the family and religious affiliation.

Pledging allegiance to a leader based on religion, place of birth and clan is a common feature of the Lebanese culture. These leaders generally exercise their authority by consensus rather than coercion and often provide services including protection (Asmar, 2011). Belonging to a certain clan or political party has consequences on an individual's personal network and the relationships that he/she maintains. The personal network, in turn, is a central element of the Lebanese culture and is exploited in all personal and professional situations from the most mundane to the most complex. Always the first resort, the personal network is the easiest and most efficient means of getting things done in the country. This goes hand-in-hand with the concept of agency whereby knowing the right people can eliminate some of the bureaucratic red tape and make

things happen faster. It also explains the prevalence of a culture of oral agreements based on trust and a disregard for formal rules.

By nature, the Lebanese individual is a social person and this is reflected in the proliferation of social activities available to the public. Material wealth and appearances play an important role in this society where any reason constitutes a good excuse to get together and party among people who are known for their hospitality and love of life. However, when it comes to their professional life, the Lebanese are driven by individualism in their quest for self-respect, ambition, success, power and social recognition (Schaaper, 2009).

In addition, the Lebanese can be described as subjective and reactive and are not above using sentiments and playing on emotions to get things done (Asmar, 2011). They are in general known for their adaptability and patience, prevarication and a complete disregard for the notion of time.

#### 2.1.11. Lebanon as an emblematic case of fragility

Lebanon is a prime example of a country in fragility and transition (Ammar et al., 2016; Asmar, 2011; Khalife et al., 2017). The country has spent the past 30 years recovering from the damages inflicted by the 15-year Lebanese civil war which lasted from 1975 through 1990 and severely impacted all aspects of the Lebanese economy including the health sector. As a result, Lebanon lost its intermediary role in the region where more than 85% of its exportations were going towards the neighboring Arab states, and had

to deal with inflation, the degradation of its public services, the exodus of its human resources and the destruction of its infrastructure including health, water, sewage and power (Kronfol & Bashur, 1989).

In addition to the weakness and fragmentation inherent in the system, the refugee crisis, which increased Lebanon's population by around 30% and put undue pressure on the infrastructure, service delivery and public finances on the healthcare system (Ammar et al., 2016; Habib, 2019), Lebanon has had to face several environmental challenges over the years which include air pollution, wildfires, periods of draught, scarcity of water in potable water and the waste crisis (Sprusansky, 2020; World Bank, 2011).

Despite everything, the Lebanese development indicators have allowed the country to enjoy the World Bank classification of upper-middle-income country (World Bank, 2021). More recently however, given the dire economic, financial and social situation in the country in the past years, the classification has been changed to that of a "fragile and conflict-affected country". The weak infrastructure, poor service delivery, institutionalized corruption and bureaucratic over-regulation compounded with the economic crisis, the October 17, 2019 popular uprising, the Covid19 pandemic and the Beirut seaport explosion have left the country grappling with increased poverty levels and higher unemployment rates. The collapse of the economy followed by the devaluation of the Lebanese pound, bank constraints on the U.S. dollar and unpaid government dues have led to problems with the retention of healthcare personnel and a limited capacity for ensuring vital equipment and medication (DeJong, 2020). Lebanon's

traditional reliance on exportation combined with low levels of local manufacturing (Khoury et al., 2020) also led to shortages in essential goods. Given the state of the economy and its heavy dependence on public spending, the once dominant private health sector now appears vulnerable and its very survival is threatened.

#### 2.2. THE RESEARCH STRATEGY

#### 2.2.1. The research questions

Therefore, the main aim of this research is to highlight and investigate the organizational challenges faced by organ donation and transplantation systems worldwide with a special focus on fragmented healthcare contexts. The thesis will respond to the primary research question "What performance management model can be proposed for an organ donation and transplantation system in a fragmented and fragile healthcare context?" This will be achieved through four sub-questions namely,

- 1. How can the performance of an organ donation and transplantation system be defined?
- 2. What performance issues can be identified in an organ donation and transplantation system in a fragmented and fragile healthcare context?
- 3. How can a PPP-based governance and regulation solution to the performance management issues of organ donation and transplantation be analyzed?
- 4. What could be the contribution of interorganizational control literature to address PPP-based governance and regulation issues for organ donation and transplantation?

### 2.2.2. Epistemology

This research follows an interpretivist paradigm which allows the progressive building of social reality as perceived by the respondents. The interpretivist worldview therefore assumes that reality is relative and the truth is subjective (Ryan, 2018). Indeed, to an interpretivist, there are multiple realities as they are all contingent personal views and experiences (Avenier, 2010; Ryan, 2018). Knowledge is not universal but rather it is socially constructed and cannot be transferred (Labonte & Robertson, 1996; Neuman & Guterman, 2016). Such knowledge is considered local, specific to the persons creating it and dependent on them for its form and content (Labonte & Robertson, 1996). Truth, within this paradigm, is not absolute, but rather it is the most informed and sophisticated construction chosen by consensus (Avenier, 2010; Labonte & Robertson, 1996). The focus is on people's lived experiences that occur in a particular context. Such a perspective supposes that reality is in fact based on human interactions and an understanding of the context in which these interactions take place (Gupta & Awasthy, 2015; Miles et al., 2014). Given that this approach yields a practical understanding of actions and their meaning it will allow the construction of the process of organ donation and transplantation and the exploration of the collaborative arrangement and regulatory mechanisms involved as perceived by the concerned stakeholders.

The researcher in an interpretivist worldview is part of the reality being constructed and the findings are created by the inquiry process rather than from external facts that already exist (Avenier, 2010; Labonte & Robertson, 1996). It is therefore meaningless to talk of objective truths (Avenier, 2010). The methodology used involves an iterative

process that constantly compares different interpretations (Labonte & Robertson, 1996) with the aim of obtaining trustworthy and authentic results (Avenier, 2010).

#### 2.2.3. Methodology

#### 2.2.3.1. Research design

Given that prior research into the topic of organ donation and transplantation has mostly focused on the ethical and marketing viewpoints and that approaching organ donation and transplantation from a process perspective is a relatively novel idea, a qualitative exploratory investigation seeking to understand the reality of organ donation and transplantation using an organizational lens was the methodology of choice for this thesis. Furthermore, qualitative strategies are well-suited for this study which sought to understand the how and why and allow the researcher to focus on subjective depictions of reality and individual perceptions of problems. Since the intent was to explore the system and better understand its problems, predominantly exploratory qualitative research was indicated.

The research design consisted of a combination of secondary analysis of existing qualitative and quantitative data embedded within an in-depth single case study design. This provided a good platform to conduct a deep dive into the problem and acquire a grasp of the phenomenon under study. This exercise was further supported by a first phase which sought to explore different organ donation and transplantation processes worldwide in an attempt to identify organizational characteristics of the process and shed light on the difficulties encountered in the implementation of organ donation and

transplantation when viewed from a managerial perspective. Using a case series design informed by a document review, four countries with different organ donation and transplantation systems were selected and studied.

#### 2.2.3.2. Choice of the case

The literature on organ donation and transplantation has mostly focused on the high-income countries with stable economies and political situations and well-developed processes of organ donation and transplantation which mostly rely on deceased donation. In an attempt to further explore the process from an organizational perspective in a fragmented healthcare system in a fragile context, the case investigated in this study is the governance and regulation of organ donation and transplantation in Lebanon. The Lebanese organ donation and transplantation system is regulated by NOD-Lb and governed through a collaborative arrangement between the MoPH and NOD-Lb as formalized in 1999 by a ministerial decree (1999, decree 509/1) positioning NOD-Lb as the only official body responsible for supervising all organ, tissue and cell donation and transplantation activities in Lebanon (*NOD-LB* /, n.d.).

Although the organ donation and transplantation process in Lebanon has been in place for more than 10 years, there has been very little research done on the system and its efficiency is poorly documented. Performance indicators consist of the commonly reported indicators including rates of donation and transplantation, conversion rates, number of donation cards, number on the waiting list, ... As such, the rates from deceased donors remain low and the process is mainly contingent on living donors,

similar to other countries in the regions. The Lebanese system however, does not mirror other systems in the region since as is the norm in this society, it has attempted to emulate Western models of organ donation and transplantation and has combined various elements that have had different degrees of success given the specific challenges of the cultural context.

#### 2.2.3.3. Sample and sampling strategy

In order to obtain a holistic understanding of the governance and regulation of the organ donation and transplantation process, all individuals who were concerned with these processes were included in this analysis. For an in-depth exploration of the collaboration between the MoPH and NOD-Lb all individuals among the NOD-Lb staff and within the MoPH that were directly involved in the collaboration process were selected. These included two individuals from NOD-LB as well as two individuals from the MoPH. A third individual from the MoPH was identified and interviewed on general governance aspects but that person did not feel qualified to contribute to the discussion about NOD-Lb since the individual had just come on board and was new to the process. The Minister of Health (MoH) was not interviewed as he was only involved at the final step in the approval and legitimization of the decisions and did not participate in the collaboration process. Moreover, the frequent changes in the Cabinet in Lebanon in recent years does not allow the MoH time to familiarize himself with the process.

To gain a better understanding of the regulatory role of NOD-Lb and the problems with the implementation of the process, all NOD-Lb staff that are involved with the process of organ donation and transplantation were recruited for analysis. This included 4 individuals that formed the core NOD-Lb team. Other individuals within NOD-Lb were not included in the sample as they primarily perform administrative routine duties that deal with the running of an office and are not directly involved in the essence of the process of organ donation and transplantation. Similarly, the president (who is usually the MoH) and the board members were not included since they are not involved in the day to day running and regulation of the process and are less likely to be aware of the challenges on the ground.

As for the choice of countries for the case series analysis, a purposive sample was chosen with the aim of achieving heterogeneity and obtaining a multiplicity of organizational structures (Creswell & Creswell, 2017; Miles et al., 2014). Countries were selected based on the international and regional influences on the Lebanese organ donation and transplantation model as well as the particularities of the various systems and the diversities due to regional and cultural characteristics. Since the Spanish model is known worldwide for its success and Lebanon like many other developing countries used it as a reference in the building of its system it is only natural that the Spanish model be explored. Lebanon was part of the SEUSA program (a consultancy program to help countries or organizations to ensure self-sufficiency in organ donation and transplantation through sharing the best practices of the Spanish- European- USA models (*Consultancy in Organ Donation | TPM – DTI Foundation*, n.d.)) and carried out numerous trainings with the Spanish TPA teams. The other European system to be explored had to be the French system as Lebanon also reached out to France for help

in continuing to improve on the Lebanese donation and transplantation system. Not only that, but Lebanon is considered as one of the francophone countries and has always held strong ties with the French nation that date back to the days of the French mandate. As such many systems in the countries still function in a similar manner to those instigated by the French government at the time. Given the mostly private nature of the Lebanese health system, the weak public sector and the evolution of the Lebanese system of organ donation and transplantation and the establishment of a collaborative form of governance it was logical to explore the US system of organ donation and transplantation for lessons learned. Finally, given the culture and geographical location of the country as well as the demographic distribution of its citizens, the religious context and the dependence on living donors, it became intuitive to also explore the Turkish system for possible parallels with the Lebanese system.

#### 2.2.3.4. Access to the field

The researcher in this thesis benefitted from enhanced access to the National Organization for Organ and Tissue Donation and Transplantation in Lebanon for several reasons. First, the Medical Director of the organization in the country, one of the pioneers in the field, was her father. This in fact, was the main inspiration for this work as the researcher observed first-hand the efforts involved in setting up the system, the satisfaction when the process performed well and the frustrations that ensued when results were not up to expectations. This afforded her a deep understanding of the process and its problems having followed the evolution of the system from its inception. This long-term engagement and the familiarity of the researcher with the team through

numerous promotional and research activities also allowed her frequent access to the research participants who were always available for in-depth discussions and further explanations. Moreover, this facilitated the acquisition of documents and data relative to organ donation and transplantation in Lebanon.

The author was able to maintain her distance by properly scheduling interviews ahead of time, following the study guide, addressing the participants formally and asking them to introduce themselves fully. In addition, the researcher had had no prior contact with the MoPH participants to whom she was introduced through her work contacts using her married name. Objectivity was achieved through the repetition of questions both formally and informally and the comparison of answers provided by different respondents through different means. Furthermore, information was validated using written documents, information on the websites, and by revisiting the audio tapes and notes taken during interviews.

### 2.2.3.5. Data collection procedure

Multiple data sources were used to collect information and consolidate evidence on the themes of interest (Noble & Heale, 2019; Whittemore et al., 2001). An extensive document review consisting mostly of technical documents and progress reports as well as a few published articles, conference presentations and proceedings, some newspaper clippings and information accessed on local and international websites was conducted. The document review also included a thorough analysis of all the laws and ministerial decrees related to organ donation and transplantation in Lebanon.

Data collection for the case series consisted of a document review that combined information from peer reviewed literature, administrative reports and country-specific organ donation related websites. A data extraction sheet was prepared (table 2.1) to ensure that comparable information was collected for each country (Vanholder et al., 2021).

Table 2.1: Data extraction sheet for the case series review

Theme	Items
1. Introduction	General description/statistics
	<ol><li>Rationale behind organ donation</li></ol>
	and transplantation in the country
	Historic development
2. Governance	Important laws
	2. Collaboration, ownership
	(public/private)
	<ol><li>Decision-making bodies,</li></ol>
	regulatory agency
	4. Financing
	5. Human resource
	6. Infrastructure
3. Service Delivery	1. Process
·	<ol><li>Strengths and challenges</li></ol>
Society and Culture	Opt-in/opt-out & consent
	2. Attitudes
	Societal
	<ul> <li>Healthcare professional</li> </ul>
	Media
	Government

Source: Author's compilation

Secondary data for NOD-Lb was analyzed using data collected from GODT, IRODAT and NOD-Lb in order to present some graphs and indicators to describe organ donation and transplantation in Lebanon. This enriched the case study by providing quantitative data to support some of the qualitative findings.

Primary data was collected from NOD-Lb through unstructured and semi-structured interviews conducted with the NOD-Lb team. The unstructured interviews consisted of several prolonged multiple-sitting interviews in the form of open-ended informal guided conversations held around the topic in various settings. Initially, these interviews served as probes to determine possible venues of investigation. Later, they were used to gather more information on particular issues that emerged from the semi-structured interviews. They consisted of individual one-on-one interviews but could also be in the form of group interviews with two or more individuals present. The unstructured interviews comprised a total of 20 hours with 4 respondents.

The semi-structured interviews, conducted in two phases, were shorter and more focused. The first phase consisted of four semi-structured interviews focused on the collaboration between NOD-Lb and the MoPH. These were conducted in the interviewees place of choice and were based on a study guide comprising 7 questions that centered around the role and responsibilities of the stakeholders, their attitudes and opinions regarding the process of organ donation and transplantation in general, the nature of the collaboration between the MoPH and NOD-Lb, the perceived benefits and barriers as well as its future (table 2.2).

Table 2.2: Semi-structured interview guide for exploring the challenges of the organ donation and transplantation process according to NOD-Lb

Question	Prompts
1. You and your role in NOD-Lb	<ol> <li>Socio-demographic information.</li> <li>What is your role/involvement in organ donation and transplantation?</li> <li>Describe step by step your role in the process on an average day</li> <li>How many times have you performed these duties?</li> </ol>
2. Define NOD-Lb	<ol> <li>Define the organ donation and transplantation program in Lebanon</li> <li>How did it start?</li> <li>What is its purpose?</li> </ol>
3. Problems/challenges faced	<ol> <li>What are the problems with the process from your perspective?</li> <li>Can you describe practical situations where you faced a problem?</li> <li>How was it resolved?</li> <li>Does this problem occur often?</li> <li>What do you think should be done to avoid such problems in the future?</li> </ol>
4. Personal views on organ donation and transplantation	<ol> <li>How do you feel about organ donation and transplantation personally? How does that affect your involvement in the process?</li> <li>Have you signed an organ donor card? Why or why not?</li> <li>Would you be willing to donate a loved one's organs upon brain death? Why or why not?</li> </ol>
5. Personal assessment of organ donation and transplantation in Lebanon	<ol> <li>What in your opinion is the real reason behind the low donation rate from deceased donors?</li> <li>What are some of the facilitators?</li> <li>What are the most important barriers?</li> </ol>

Source: Author's compilation

The second phase consisted of interviews pertaining to the regulatory role of NOD-Lb. These were conducted one-on-one in the NOD-Lb offices and based on a study guide comprised of 5 main questions that were meant to stimulate discussions about the program of organ donation and transplantation as a whole, the role and responsibilities of the respondents, descriptions of particular problems that they faced in the implementation of the process and their own attitudes and opinions regarding the process in general and organ donation and transplantation in particular (table 2.3).

Table 2.3: Semi-structured interview guide for exploring the characteristics of the collaboration between NOD-Lb and MoPH

	Question		Prompts
1.	Opinion on organ donation and transplantation	2.	What is your vision of organ donation and transplantation in general? What is your vision of organ donation and transplantation in Lebanon? What is the vision of your organization?
2.	Development of NOD-Lb	3.	Why NOD-Lb? How did it come about? What were the factors that led to its development? What were the factors that shaped its present form?
3.	Roles	1. 2.	What is the role of NOD-Lb? What is the role of MOPH?
4.	Collaboration		Describe the process of collaboration between NOD-Lb & MoPH What are the benefits and barriers of this collaboration? What was accomplished due to this collaboration?
5.	Evaluation of the Collaboration		What is your perception of the collaboration between NOD-Lb and MOPH? What is the future of this collaboration? Any suggestions for improving it?

Source: Author's compilation

All interviews were conducted by the author, in spoken Arabic (Lebanese mixed with English and French expressions), after informing the respondents of the objectives and importance of the study and obtaining their oral consent. The semi-structured interviews were recorded with permission. They lasted from half an hour to two hours. The interview guides were further elaborated during the interviews to allow the exploration of new topics that emerged. Some respondents were re-interviewed for emphasis and clarification. In total, the semi-structured interviews consisted of 10 hours of interviewing for 10 interviews conducted with 6 participants.

The interview guides, which were elaborated in English, were translated into Arabic using back translation (Haccoun, 1987). The Arabic versions were pilot tested prior to use to determine their clarity. No changes were deemed necessary after pilot testing.

Upon completion of the interview, the investigator kept reflective memo-notes to document particular observations pertaining to the respondents' attitudes and the logistics of the interview. The interviews were transcribed verbatim in Arabic and the transcripts were shared with some of the interviewees for validation (Noble & Smith, 2015).

The data collection sources are summarized in figure 2.1 below.

Document review	Secondary data	Informal interviews	Semi- structured interviews	Observation
<ul> <li>Published articles</li> <li>Grey literature</li> <li>Manuals</li> <li>Conference presentations</li> <li>Newspaper clippings</li> <li>Websites</li> <li>Administrative reports</li> <li>Laws</li> </ul>	<ul> <li>International websites</li> <li>Administrative reports</li> <li>Country websites</li> </ul>	Open-ended informal guided conversations Probes and details individual one-onone or group interviews 4 respondents	<ul> <li>Two phases</li> <li>Study guides</li> <li>10 interviews</li> <li>6 respondents</li> </ul>	Visit to office     Passive presence during informal meetings     Attending conferences
	10 hrs	20 hrs + weekly discussions	10 hours	4 hours

Figure 2.1: Data collection sources

Source: Author's compilation

### 2.2.3.6. Analysis

An abductive strategy was used to guide the analysis. All interviews were transcribed in Arabic but coded in English. Initial codes were generated based on the answers to the questions posed and later reorganized inspired by existing organizational frameworks. As a next step, they were further adjusted informed by empirical data and driven by insights obtained through going back and forth between the theory and the empirical evidence (Eisenhardt & Graebner, 2007). Working the data from the ground up, empirical evidence was labeled and categorized into common themes in order to define the collaboration between NOD-Lb and the MoPH in the promotion of organ donation and transplantation in Lebanon, understand the regulatory role of NOD-Lb and identify the problems faced by the organ donation and transplantation process in Lebanon.

Moving back and forth between empirical evidence and identified theoretical frameworks, agency and collaboration theories were applied to develop an emergent framework that explains the complexity of the collaboration between the private and public sector in the governance and regulation of the organ donation and transplantation process in Lebanon. This is in line with the study's objectives to develop new insight into the challenges facing organ donation and transplantation in fragmented healthcare systems by using case study research to develop direction for new theory and provide evidence that can be used inform the ministries, organ donation and transplantation regulatory agencies and other stakeholders who are addressing operational issues with very little direction from the existing literature (El-Jardali et al., 2012; Sheikh et al., 2020).

The use of a case study protocol, allowed for in-depth comprehension and analysis (Yin, 2014). In addition, triangulation, employing multiple sources of evidence, following the chain of evidence and having key informants review and corroborate the findings helped ensure the validity of the evidence and rigor of the analysis (Noble & Smith, 2015; Whittemore et al., 2001).

Part I has argued for the analysis of organ donation and transplantation systems from a performance management perspective. This section has highlighted the challenges in fragmented healthcare systems in fragile contexts and proposed the Lebanese system as an emblematic case for this study. Part II will proceed to answer the research questions put forth in this section.

## PART II: ORGANIZATIONAL CHALLENGES OF PERFORMANCE MANAGEMENT IN ORGAN DONATION AND TRANSPLANTATION SYSTEMS IN AN EMBLEMATIC CASE OF FRAGMENTATION AND FRAGILITY

The objective of part II is to answer the first two research questions put forward in this thesis namely, "How can the performance of an organ donation and transplantation system be defined?" and "What performance issues can be identified in an organ donation and transplantation system in a fragmented and fragile healthcare context?".

This section is divided into two chapters. Chapter 3 presents a structured review, using a performance management lens, of organ donation and transplantation systems in the four countries. This underscores the importance of the governance dimension in all the organ donation and transplantation models and generats evidence on the limitations of performance management systems in each country. Chapter 4 applies the same frameworks to analyze the performance management of an organ donation and transplantation system in a fragmented healthcare setting within a fragile context by focusing on the Lebanese organ donation and transplantation system. This chapter ends by comparing the Lebanese system to the systems previously described focusing on the gaps in performance management systems and the challenges of governance.

### CHAPTER 3: A STRUCTURED REVIEW OF THE PROBLEMS FACED BY ORGAN DONATION AND TRANSPLANTATION MODELS: A

PERFORMANCE MANAGEMENT PERSPECTIVE

Applying a managerial lens for scrutinizing the various systems, this chapter specifically focuses on organ donation and transplantation as a process, highlighting different governance and regulation mechanisms while taking into account the legislation, policy and cultural aspects that impacted both living and deceased donation processes. To achieve this, the different organ donation and transplantation systems will first be described in detail along the lines of the governance model proposed by Mikkelsen-Lopez et al. (2011) by focusing on the three levels of service delivery, governance and society. As a second step, they will be analyzed and compared using the Performance Management System Framework proposed by Ferreira and Otley (2009).

There are now around 86 countries around the world that are members of the global observatory on donation and transplantation and are actively involved in the transplantation of organs and the promotion of organ donation (figure 3.1). However, donation rates vary from country to country based on particular contextual factors including religious, cultural, societal, legal and organizational tendencies (Giwa et al., 2017; Manyalich et al., 2011; Vanholder et al., 2021). For example, the highest total transplantation rates are found in the USA (123 per million population (pmp)) and Spain (117 pmp) in comparison to around 57 pmp for Europe, 64 pmp for America and 28 pmp worldwide (*GODT - Global Observatory on Donation and Transplantation*, n.d.).

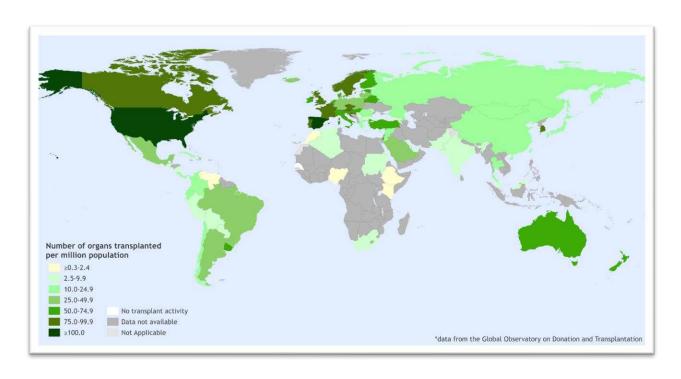


Figure 3.1: Global Transplantation Activities of Solid Organs 2018

Source: GODT Executive Summary 2018

Transplantation rates vary by type of donor with the majority being from living donors as transplantation from deceased donors remains low failing to meet the need for transplantable organs in all countries and even being almost non-existent in some (Rudge et al., 2012). In 2019, the highest transplantation rate from deceased donors was in Spain (49 pmp) while the lowest was in the Philippines (0.09 pmp) (*IRODaT* - *International Registry on Organ Donation and Transplantation*, n.d.). On the other hand, transplantation rates from living donors were highest in Turkey and South Korea with rates of 53 and 52 pmp respectively and lowest in Paraguay with a rate of 0.85 pmp.

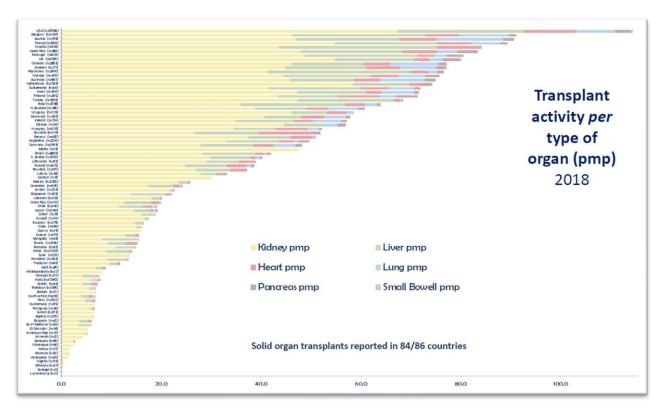


Figure 3.2: Transplant activity per country per type of organ (pmp) in 2018

Source: GODT Executive Summary 2018

The rate of transplantation from living donors in Spain was around 7 pmp while the rate of transplantation from deceased donors was 8.7 in South Korea and 7.5 pmp in Turkey. Moreover, transplantation rates vary by organ (figure 3.2) with the kidney accounting for approximately 65% of all transplant activity globally while the small bowel accounts for only 0.1% of the global transplant activity (GODT, 2020).

A comprehensive management of the organ donation and transplantation process entails a detailed understanding of its governance structure and performance management systems. Using the frameworks detailed in the previous chapter, this chapter presents an overview of four organ donation and transplantation systems

chosen due to the diversity of their governance mechanism and regulatory bodies, their success in organ donation and transplantation and on the basis of their influence on or similarities with the Lebanese system. This chapter reviews organ donation and transplantation practices in countries that have managed to achieve high donation rates from deceased donors (Spain and France), living donors (Turkey) or both (United States of America) as shown in figures 3.3 and 3.4.

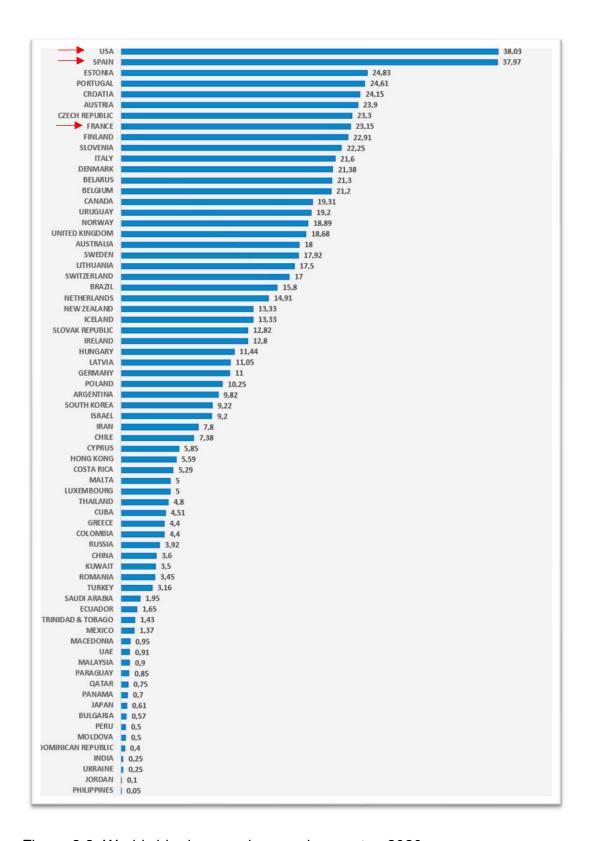


Figure 3.3: Worldwide deceased organ donor rates 2020

Source: IRODaT, 2022

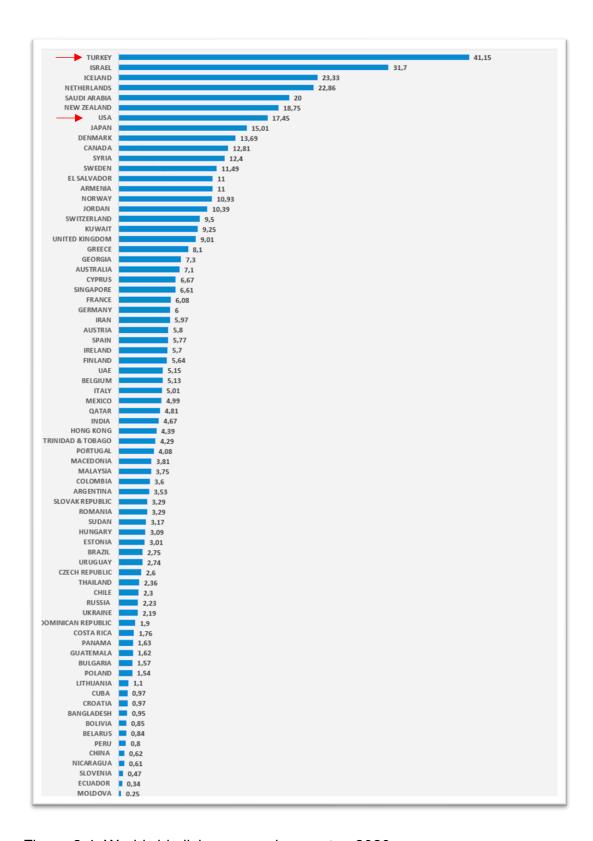


Figure 3.4: Worldwide living organ donor rates 2020

Source: IRODaT, 2022

### 3.1. THE UNITED STATES OF AMERICA

Organ donation in the USA started more than 150 years ago with tissue transplants followed by living donation and shortly after deceased donation (*Quick Organ and Tissue Transplant History*, 2020; *Timeline of Historical Events and Significant Milestones | Organdonor.Gov*, n.d.). It is only then, due to increased activity, that the need for regulation arose and saw the enactment of the Uniform Anatomical Gift Act (UAGA) in 1968. The first skin transplant took place in 1869 and the first kidney transplant from a live donor in 1954. In that same year the Navy established the first tissue bank that allowed storage of tissues for later use for the purposes of healing people in need of grafts. The first successful deceased donor transplant took place in 1962 for the kidney and 1967 for the liver.

Prior to 1984, organ allocation was limited to an informal attempt to share organs between transplant hospitals in order to increase the donation and transplantation potential in the country by making better use of the limited organs available. The government recognizing the need for a more organized process took the necessary steps to develop a national system with rules for matching and distributing organs as well as means to collect and store data on donation and transplantation. Therefore, with this in mind, the congress passed, in 1984, the National Organ Transplant Act (NOTA) which gave rise to the organ procurement and transplantation network (OPTN) and scientific registry of transplant recipients (SRTR), the two main non-governmental structures concerned with regulating organ donation in the USA.

Today, the USA has one of the highest donation rates from both deceased and living donors with donation rates (National Data - OPTN, n.d.), transplantation, waitlist numbers and deaths remaining relatively stable over the past decades (Lewis et al., 2021). These rates vary by state and although the country has made considerable efforts to ensure equity in the allocation of organs there are still disparities (Equity in access report 201611.Pdf, n.d.; Stewart et al., 2016, 2018). In 2019, there was an approximate 9% increase in the rate of transplants relative to 2018 (OPTN) *Metrics*, n.d.) yet, the demand for organs remained higher than the availability with 19,736 transplants performed in 2019 relative to the 113,000 patients in need of a transplant in that year (Lewis et al., 2021). Around 83% of the individuals on the waiting list were waiting for a kidney and 59% were of ethnic minority. Challenges remain especially in terms of allocation by area of the transplant hospital and candidate compatibility, blood type and diagnosis (*Equity in access report 201611.Pdf*, n.d.). Fifty-eight percent (58%) of the US population were registered as potential donors and the waiting time for an organ ranged from 213 to 370 days and varied by organ (Lewis et al., 2021). Furthermore, a total of 4925 individuals died while waiting for a transplant. It is estimated that the annual cost of all transplant recipients in the US will be 332.7 million dollars in 2020.

Although the living donation rate is relatively high at 22.99 pmp in 2019, deceased donation remains more prominent with 36.88 pmp in 2019 (*IRODaT - International Registry on Organ Donation and Transplantation*, n.d.). Therefore, despite the fact that there were a few years (2001-2003) where living donors outnumber the deceased ones,

the latter still provides most transplanted organs in the country (Ersoy et al., 2021; Nathan et al., 2003). In 2019, deceased donors contributed to 81% of all transplants and comprised 62% of donors in the USA for that year with 16,028 transplants from deceased donors compared to 3,708 transplants from living donors and (*OPTN Metrics*, n.d.). The majority of the donors were kidney donors which accounted for 94% and 93% of all deceased and living donors respectively (*National Data - OPTN*, n.d.).

### 3.1.1. Service Delivery and Society and Culture

The transplant system in the USA consists of a network of transplant centers, organ procurement organizations, and donor hospitals (Wynn & Alexander, 2011). Transplant centers are most often affiliated with academic hospitals while the donor hospitals are usually non-academic. In general, transplant centers and donor hospitals are independent of each other. Each donor hospital has a single designated OPO with which it works to promote organ donation and recovery.

### 3.1.1.1. Living Donation System

Living donors can potentially donate one or a part of the following organs: kidney, liver, lung pancreas or the intestines, as well as some tissues such as skin, bone, healthy cells from bone marrow and umbilical cord blood, amnion, blood, including white and red blood cells, platelets, and serum (*The Living Donation Process | Organ Donor*, 2018). Living donors in the USA can include both blood (parent or sibling) or non-blood (spouse) relatives as well as non-relatives namely friends or even strangers (*The Big Ask, The Big Give | National Kidney Foundation*, n.d.). Most living donations however,

happen among family members or between close friends (*The Living Donation Process* / *Organ Donor*, 2018). Those who choose to donate to someone that they do not know do so altruistically as a gift since living-donor organs are not considered public resources and therefore cannot be purchased or sold (Reese et al., 2015).

The suitability of a living donor is carefully evaluated by the transplant team at the center where the donation will occur. The donor is assessed for possible adverse physical, psychological, or emotional outcomes that might transpire before, during, or after the donation. In general, living donors should be in good health, between the ages of 18 and 60 and physically fit. They should not have any history of diabetes, cancer, high blood pressure, kidney disease, or heart disease. The process is guided by ethical principles to protect the donor who should be capable of making an informed decision and providing consent to the donation without coercion (Reese et al., 2015). The donor must be well appraised of the fact that the donation process will involve a major surgical procedure with all the risks and financial burdens that it entails. As part of the psychological evaluation, the transplant team should probe into the motives, commitment and appreciation of the donor for the risks and benefits of the process.

Regulation of living donation mostly focuses on safety and there are no specific policies governing the allocation of organs from living-donors (Ersoy et al., 2021). Due to careful screening and evaluation prior to donation approval, all retrieved organs are used and the organ recipient is usually chosen by the donor.

### 3.1.1.2. Deceased Donation System

Deceased organ donors are patients with extensive brain injury that is usually the result of a cerebro-vascular accident, trauma or anoxia. In keeping with federal regulations and as stipulated by the final rule, hospitals are required to immediately refer cases of death or near death to the OPOs of the cases ("Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals' Provision of Transplant-Related Data--HCFA. Final Rule," 1998). Eligible individuals are deceased patients 70 years old or younger, who do not have any exclusion criteria for donation and are declared legally brain dead by neurologic criteria and tests (Girlanda, 2016). The deceased donation process in the USA follows six steps namely, brain injury, referral, brain death, consent to donation, organ recovery and organ transplantation (Girlanda, 2016) and the potential for losing donors is inherent at each step.

Upon referral, the OPO takes charge of coordinating all aspects of the donation including logistic, medical and regulatory. OPO procurement coordinators travel to the hospital (*The Deceased Donation Process | Organ Donor*, 2018) to oversee the donation and transplantation process and work together with the hospital medical staff to maintain the deceased patients' organs. Proper management of the potential donor in the intensive care unit (ICU) is essential to the preservation of organs and will subsequently affect the quality of the procured organ and its function after transplantation (Girlanda, 2016).

In accordance with the ethical principles of autonomy and non-maleficence, the OPO procurement coordinator approaches the family of the donor about the possibility of donation and provides support from the time of referral until after the donation has taken place. If the deceased has expressed the will to be an organ donor after death through registration with the state of residence or at the department of motor vehicles this is considered as legal consent to donation (*The Deceased Donation Process | Organ Donor*, 2018). Otherwise, the OPO representative will ask for authorization from the next of kin. This is a critical step in the process due to its repercussion on number of donated organs and its impact on future strategies to increase donation (Girlanda, 2016). Efficient communication with the parents and timely consent also highlights the importance of effective coordination between ICU providers and OPO personnel.

Upon consent, a complete medical evaluation takes place. Based on clearly established criteria indicated in the United Network for Organ Sharing (UNOS) policy (*Optn\_policies.Pdf*, n.d.), the deceased is evaluated for medical eligibility for donation. If deemed suitable, the OPO contacts the OPTN which operates the US national waiting list for transplantation (*The Deceased Donation Process | Organ Donor*, 2018) and an electronic search for a list of the most suitable potential match for the deceased donor's organs is initiated.

The rules for organ allocation are set by OPTN/UNOS, and they vary by organ and are determined based on the urgency and degree of severity of the candidate requiring the transplantation (Girlanda, 2016). An algorithm per organ is used and patients in the waiting list data base are matched to the donor prioritizing the OPO donation service

area (DSA), blood type and time spent on the awaiting list (Nathan et al., 2003; *Optn\_policies.Pdf*, n.d.). Other considerations include the medical status for heart and liver recipients, tissue typing and compatibility for kidney transplants and donor weight for non-renal organs. In terms of region, the priority is for the local OPO service area, then regionally, then nationally.

The deceased donor's organs are offered to the transplant team of the best-matched patient (*The Deceased Donation Process | Organ Donor*, 2018). It is the responsibility of the transplant surgeon to determine whether the organs are medically suitable for a particular patient. In certain situations, if the patient is too sick or cannot be reached on time the surgeon may refuse the organ.

The transplant surgical team in charge of organ recovery is different from the medical team that was previously attempting to save the patient's life. Moreover, multiple organs are procured in different combinations during a multi team operation that lasts several hours (Girlanda, 2016). Each team carries the burden of recovering the respective organ in the best possible condition for their intended recipient. Therefore, excellent communication and coordination between teams is essential during procurement.

Once the organs are recovered the OPO organ procurement coordinator arranges for their rapid and efficient transportation to the hospitals of the intended recipients where the latter are usually in the operating room awaiting the arriving organs (*The Deceased Donation Process | Organ Donor*, 2018). Unfortunately, due to various reasons

including inadequate management, damaged organs, unsuitable organs or recipients, not all recovered organs are always transplanted. In 2019, there were 3.51 organs recovered and 3.01 organs transplanted per donor with 14.3% discarded organs per recovered organ (Israni et al., 2021).

### 3.1.1.3. Society and Culture

The USA subscribes to the Western model for organ donation which is based on altruistic donation and is independent of material gain (Capron, 2014). Organ donation in the USA operates under an "opt-in" system and presumes that, during their lifetime, individuals should explicitly declare their consent to become donors after their death (Ahmad & Iftikhar, 2016). The consent rate in 2016 varied by OPO from 65% to 93% with an average of 76% (Girlanda, 2016). It is expected that attempting to move to an "opt-out" system in the US would be faced by considerable opposition on both the political and religious fronts.

In terms of knowledge and attitudes, the USA public lacks the basic knowledge necessary to plan ahead and make informed decisions with respect to organ donation (Ahmad & Iftikhar, 2016). Evidence suggests that in people in general are not aware of the urgency of the situation, the availability of both living and deceased systems, which organs can be donated, and the time, effort and risk involved in the donation process. Moreover, there are limited programs working on educating the population.

### 3.1.2. Governance and Regulation

Organ donation in the United States is overseen by a federal entity known as the Division of Transplantation (DoT) which is housed within the Department of Health and Human Services (HHS), as part of the Health Resources and Services Administration's (HRSA) Healthcare Systems Bureau (*About the OPTN - OPTN*, n.d.; Capron, 2014; Nathan et al., 2003; Scandling & Norman, 2010; Wynn & Alexander, 2011). DoT is in charge of the national organ and blood stem cell transplant system and all activities pertaining to increasing donation rates (*About the OPTN - OPTN*, n.d.). DoT programs include the organ procurement and transplantation network, the scientific registry of transplant recipients, promoting public awareness for organ donation and the C.W. Bill Young transplantation program that provides support to patients who need a bone marrow or umbilical cord blood transplant.

# 3.1.2.1. The Organ Procurement and Transplantation Network (OPTN) Following NOTA, the OPTN, an entity tasked with the maintenance of the national registry for organ matching, was established as a public-private partnership in an effort to counter organ shortage and improve organ matching and placement in the US (*About the OPTN - OPTN*, n.d.; Ersoy et al., 2021; Nathan et al., 2003; Scandling & Norman, 2010; Wynn & Alexander, 2011). As a result, the OPTN which connects all organizations and individuals involved in organ donation and transplantation, is run by a private non-profit organization under federal contract to the HHS. In 1986, after soliciting proposals as per the recommendations of a task force commissioned through NOTA, the HSS contracted the United Network for Organ Sharing (UNOS) to operate the

OPTN based on a regulatory framework established by the HSS in 2000 (*About the OPTN - OPTN*, n.d.; Nathan et al., 2003).

The OPTN manages organ donation with the aim of maximizing organ supply, ensuring accessible, effective and safe care, allocating organs equitably and promoting public trust through transparent and inclusive strategies. The OPTN is run by a board and a number of committees ((About the OPTN - OPTN, n.d.). The board is responsible for establishing and maintaining both the bylaws and transplant policies. The committees, on the other hand, focus on specific issues of concern such as pediatric transplantation, patient affairs, policy oversight and a committee specific to the transplantation of each organ among others. Figure 3.4 depicts the policy development process (Optn-Policy-Development-Process-Explanatory-Document.Pdf, n.d.). Two important components of policy development include evidence gathering and public comment suggesting a genuine attempt to propose evidence-based policies that respond to the users' needs. In addition, there are steps for implementing the policy which includes the education of the public on the key information included in the policy as well as a final step for reviewing the effectiveness of the policy. Figure 3.5 provides an updated list of OPTN policies (Optn policies.Pdf, n.d.). There are a total of 20 policies intended to facilitate the governance and regulation of organ donation. Each policy is specific to a particular issue and is clearly stated in full detail and readily available online.

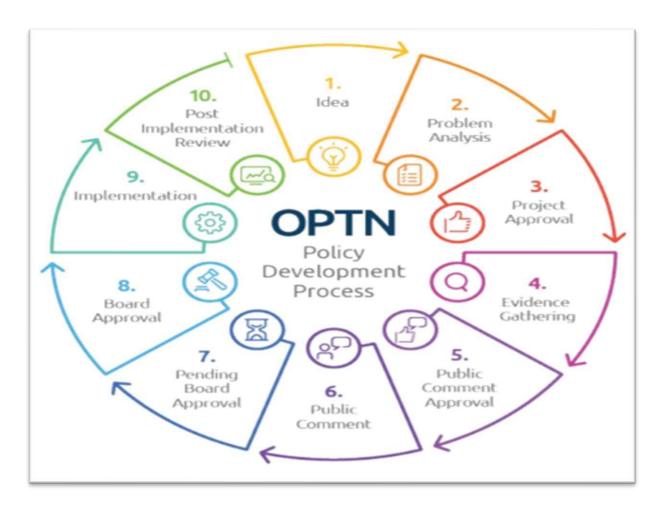


Figure 3.5: OPTN policy development process

Source: https://optn.transplant.hrsa.gov/media/3115/optn-policy-development-

process-explanatory-document.pdf



Figure 3.6: OPTN policies 2021

Source: <a href="https://optn.transplant.hrsa.gov/media/1200/optn">https://optn.transplant.hrsa.gov/media/1200/optn</a> policies.pdf

### 3.1.2.2. United Network for Organ Sharing (UNOS)

The UNOS is a private, nonprofit organization that serves through its 11 regions as the link between organ donors and recipients (*United Network for Organ Sharing | Children's Hospital Pittsburgh*, n.d.). This encompasses the whole continuum of services included in the organ donation process and includes not only patients that have been transplanted or are awaiting transplantation and their donors but also the health personnel and technicians who specialize in donation and transplantation, friends and families of transplant patients, recipients and donors, healthcare volunteers as well as

all members of the general public who support donation and transplantation. To accomplish this, every donor hospital, transplant center, OPO and histocompatibility lab in the US is a member of UNOS (Ersoy et al., 2021; Nathan et al., 2003; Scandling & Norman, 2010; Wynn & Alexander, 2011) and agrees to abide by all OPTN obligations. UNOS is responsible for conducting routine evaluations to ensure member compliance with the requirements and proceeds to thoroughly investigate all non-compliant instances (OPTN Member Evaluation Plan.Pdf, n.d.). In addition, UNOS is responsible for maintaining the national organ transplant waiting list and matching and distributing organs, collecting and analyzing data on transplant recipients and donors to advance transplantation science and practice, increasing public awareness, educating the public and medical professionals on donation and transplantation and developing standards and policies. The latter are based on two overarching goals namely achieving justice in organ allocation and balancing equity and utility (Scandling & Norman, 2010). UNOS funding is mostly private based on its operating budget and membership fees, numerous charitable contributions and various grants from foundations and corporations. Only 15% of the funding comes from the federal government (United Network for Organ Sharing | Children's Hospital Pittsburgh, n.d.). Several systems around the world, including those of the United Kingdom, Germany, Spain and Canada, were modeled after the UNOS.

### 3.1.2.3. The Organ Procurement Organizations (OPO)

OPOs are non-profit organizations that are legally permitted to recover organs from deceased donors and are responsible for their clinical management (Ersoy et al., 2021; Kazemeyni et al., 2009; Nathan et al., 2003; *Organ Procurement Organization (OPO)* 

Conditions for Coverage Final Rule: Revisions to Outcome Measures for OPOs CMS-3380-F | CMS, n.d.). Their main duties consist in the identification, evaluation, and management of brain death cases as well as the preservation, conservation, packaging and transfer of organs to transplant hospitals. They also carry out whole tests and tissue typing and compatibility and work with other agencies to identify potential transplant recipients and share organs. In addition, OPOs are responsible for obtaining consent from and providing support to the donor's family as well as providing education about organ donation to both healthcare professionals and the general public. OPOs are the central component in the process of donation and transplantation as they interact with the public as well as various healthcare providers and regulatory bodies (R. J. Howard et al., 2012).

According to federal law, OPOs are surveyed and recertified by the Centers for Medicare and Medicaid Services (CMS) based on specific outcome and process measures every four years. To avoid being decertified and continue receiving payments for services, OPOs must conform with the recommendations of the surveys and proceed to correct any problems or deficiencies cited. Since each OPO is responsible for recovering organs from all hospitals in federally-designated contiguous geographical DSAs, regulations ensure that a DSA is always served by an OPO. If an OPO is decertified, its DSA is transferred to one or more of the other OPOs that are assigned either through competition or by the CMS.

There are currently 58 OPOs, in the USA that provide all of the deceased donor organs to the 248 transplant centers in the country. The majority of the OPOs are private, nonprofit organizations.

### 3.1.2.4. The Scientific Registry of Transplant Recipients (SRTR)

The Chronic Disease Research Group, under contract from DoT, operates the SRTR whose role is to provide advanced statistical and epidemiological analyses related to solid organ allocation and transplantation in order to support HHS in overseeing the national organ transplantation system (*Mission, Vision, and Values*, n.d.). According to section 373 of the Public Health Service (PHS) Act, the SRTR is required by law to provide analytical support to the OPTN to inform organ allocation and support the evaluation of solid organ transplantation. In addition, SRTR provides evidence-based results to HHS for use in formulating policies, evaluating system performance, performing economic analysis and reporting to Congress.

### 3.1.2.5. Legislation and Policy

There are three laws that act as the cornerstone of US legislation regarding organ donation namely the UAGA which was passed in 1968 and amended in 2006, the Uniform Determination of Death Act passed in 1980 to replace the Uniform Brain Death Act of 1968 and Public Law 98-507 the NOTA passed in 1984 (*Selected Statutory and Regulatory History of Organ Transplantation | Organ Donor*, 2018). The NOTA provides the regulatory framework for the three main organ donation entities that form the system

of organ donation in the USA without actually specifying a particular mechanism for the allocation of organs. Table 3.1 summarizes the three laws.

Table 3.1: Important legislature for organ donation and transplantation in the USA

Law	Year	Description
Uniform Anatomical Gift Act (UAGA)	1968	A model statute, intended for adoption in every jurisdiction. This law provided the legal foundation upon which human organs and tissues can be donated for transplantation by execution of a document of gift. Deemed a person's legal consent to donate before death sufficient under the law (without an indication that the consent was no longer valid).
	2006	This model law legally bars others from revoking the consent of a donor after death who legally registered as a donor during his or her lifetime (without an indication that the consent was no longer valid).
Uniform Determination of Death Act	1980	A model statute, intended for adoption in every jurisdiction, that replaced the Uniform Brain Death Act (which did not address traditional criteria for determining death). The Act states that an individual who has sustained either (1) irreversible cessation of circulatory or respiratory functions, or (2) irreversible cessation of all functions of the brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.
National Organ Transplant Act (NOTA)	1984	Public Law 98-507 Provided for the establishment of the Task Force on Organ Transplantation, authorized the Secretary of Health and Human Services to make grants for organ procurement organizations, created the Organ Procurement and Transplantation Network (OPTN) to be run by contract by the Secretary of Health and Human Services, created the Scientific Registry of Transplant Recipients, and created an administrative unit within the Department of Health and Human Services to administer these activities. Section 301 of NOTA included the criminal prohibition against the exchange of organs for transplantation for valuable consideration.

Source: https://donaciondeorganos.gov/about-dot/laws/history.html

### 3.1.2.6. Financial Coverage

Surgery is covered by Medicare or the recipient's insurance (The Big Ask, The Big Give | National Kidney Foundation, n.d.). However, other expenses such as travel, lodging, meals and incidentals, lost wages, child-care and elderly-care need to be taken into account. The Living Organ Donation Reimbursement Program, is a national program, administered by HRSA, that reimburses eligible donors for such expenses when related to the donor's evaluation, surgery, and follow-up visits (The Living Donation Process | Organ Donor, 2018). In addition, the National Living Donor Assistance Program (National Living Donor Assistance Center > Resources > Learn About Organ Donation, n.d.) may help cover travel and lodging costs. Finally, donors may be eligible for sick leave, state disability, and benefits under the federal Family Medical Leave Act. All federal and some state employees and other workers may be eligible for 30 days paid leave. However, contrary to other higher income countries, there is no nationally sanctioned mechanism in the USA to provide these funds.

### 3.2. SPAIN

Spain is considered as a reference in organ donation and transplantation (Coelho & Bonella, 2019; *History of the ONT*, n.d.; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999) and has been a world leader for the last decades managing to sustain the highest donation rate in Europe and in most instances in the world. Spain's success can be attributed to the efforts of the National Transplant Organization (ONT) and the implementation of what is known today as the Spanish Model as organ donation rates began rising in Spain with the establishment of the ONT

and the introduction of transplant coordinators. In fact, these elements paved the way for Spain to double its deceased donation rate and maintain a privileged position in less than a decade (Matesanz et al., 2017).

Organ donation began in Spain in 1965 with the first renal grafts performed in Barcelona and Madrid (*History of the ONT*, n.d.; Miranda, Lucas, et al., 1999). The ONT was established in 1989 and soon after transplant donor coordinators were introduced as an integral component of an organ donation model with three levels of coordination namely national, regional and local.

In 2019, Spain had a deceased donation rate of 49.6 pmp, a living donation rate of 7.17 pmp (*IRODaT - International Registry on Organ Donation and Transplantation*, n.d.) and a transplant rate of 114.8 patients per million inhabitants with a total of 4,818 transplants performed in that year, 69% of which were kidney transplants (*Spain*, n.d.). There were around 2.3 thousand donors registered in Spain in 2019 with 10,577 on the waiting list. Median waiting time is 42 days for a liver and up to 251 days for a pancreas. Donation and transplantation rates vary by autonomous communities. For example, in 2020, the highest donation rates were in Cantabria while the highest transplantation rates were found in Catalonia for the kidney, liver, lung and pancreas and in Madrid for the heart. In 2021, the budget expenditure of the Ministry of Health in Spain amounted to approximately 3.1 billion euros.

### 3.2.1. Service Delivery and Society and Culture

The philosophy behind the Spanish Model consists in acknowledging that the principal limitation in organ donation is the shortage of organs and the main reason behind the latter lies in the failure to convert potential donors into actual ones rather than in the scarcity of donors (Miranda, Lucas, et al., 1999; Rudge et al., 2012). That being the case, the Spanish model of organ donation approaches the process of deceased donation in a systematic and organizational way (Matesanz, Domínguez-Gil, et al., 2011) with the main intent being the reduction in organ shortage through the optimization of the deceased donation process (Miranda, Lucas, et al., 1999). It has aptly been described as "a model of people and resource management" (Coelho & Bonella, 2019) that is based on an extensive network of hospital coordinators trained in the early detection of potential donors and equipped with appropriate communication skills to secure familial consent. The strength of the model lies in it being developed in conjunction with appropriate legal, technical and political frameworks (Matesanz & Dominguez-Gil, 2007)

Figure 3.6 presents the Spanish process for deceased organ donation (Miranda, Lucas, et al., 1999). What is clear in this representation is that the Spanish believe that both the starting and end points of the organ donation process are the society. Indeed, it is the people that act as the driving force for organ donation and they are the main beneficiaries from the process. The health professionals are in essence merely facilitators whose role is to ensure that donors and recipients get a chance to meet.

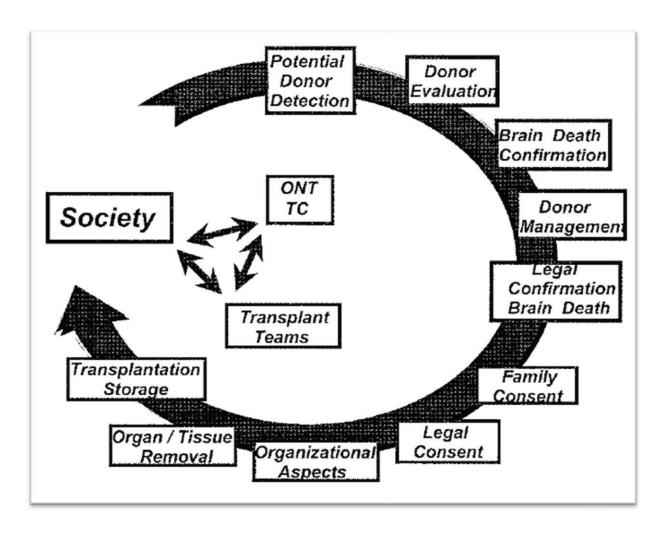


Figure 3.7: Steps in the donation and transplantation process

Source: Miranda, Lucas, et al., 1999

Since Spain relies predominantly on deceased donors and the larger proportion of all deceased donations in Spain come from brain dead donors, the Spanish Model focuses on enhancing conversion through centralizing its efforts on the early detection of potential donors (Chang et al., 2003; Matesanz, 2003; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999; Rudge et al., 2012). To do so, it targeted the most likely location of donors which is the ICU and capitalized on the professionalization of the process by engaging intensivists and training them as in-house transplant

coordinators who are in charge of the whole donation process in the hospital from detection to consent. In conjunction with the early detection of potential donors, particular attention is also paid to donor management and family consent, two other steps in the process which were identified as probable areas where donors could be lost (Miranda, Lucas, et al., 1999).

Three additional components characterize the Spanish Model for organ donation and these include the quality assurance program, the professionalization of organ donation and the relationship with the media (Matesanz, 2003; Matesanz & Dominguez-Gil, 2007). These components will be discussed in more detail under governance.

Although the success of organ donation in Spain has been mostly attributed to its legislature and opt-out policy, it is clear that there is more to it than that especially since the Spanish legislation, has remained unchanged since 1979 (Matesanz, 2003). It is true that Spain endorses an opt-out system however, in practice it is a qualified opt-out since the families of the deceased are always consulted and their consent is obtained before proceeding with organ procurement (Miranda, Lucas, et al., 1999; Rodríguez-Arias et al., 2010). Society, education, media, the economy, the healthcare system and health professionals play an important role in the endorsement and promotion of organ donation (Manyalich et al., 2011).

Society forms the beginning and end of the vital cycle (figure 3.7). Societal attitudes initiate the process of organ donation and societal evaluation in terms of program

results, quality of life, and survival allow the evolution and continuation of the process. The Spanish society exhibits a positive attitude towards organ donation that is reinforced by cultural, religious, economic and educational factors. Around 72% of respondents in Spain would be willing to donate their organs to help others in the event of their death and only 8% were altogether against organ donation (Ipsos, 2018). Moreover, the family refusal rate has remained stable varying between 20% and 25% over the past few years. Donation is considered an altruistic act which is strongly endorsed by the government, healthcare professionals and the media (Manyalich et al., 2011).

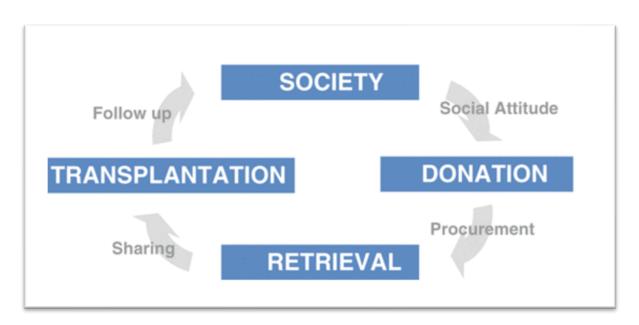


Figure 3.8: The vital cycle

Source: Manyalich et al., 2011

# 3.2.2. Governance and Regulation

In 1989, around twenty years prior to the WHO call for organ self-sufficiency, the Organizacion Nacional de Trasplantes (ONT) was created by the Spanish Ministry of Health as an organization attached to the Spanish Department of Health (Matesanz et al., 2017; Miranda, Lucas, et al., 1999). This public agency is in charge of the coordination and oversight of donation, procurement, and transplantation activities (Matesanz et al., 2017). In an attempt to perform these tasks efficiently, the national transplant coordinating network with decentralized donor coordination at three levels namely national, regional and local, was devised (Chang et al., 2003; Matesanz, 2003; Matesanz, Domínguez-Gil, et al., 2011; Matesanz & Dominguez-Gil, 2007; Miranda, Lucas, et al., 1999). Whereas the local level, which consists of a network of officially authorized hospitals that are directly responsible for implementing the deceased donation process, comprises most of the technical weight, the regional and national levels act as the link between the technical and political entities involved in the process (Matesanz, Domínguez-Gil, et al., 2011).

#### 3.2.2.1. National Coordination

The central office of the ONT acts as a service agency for the entire National Health System, ensuring the continued availability of organs, tissues and cells for transplantation and guaranteeing the most appropriate allocation based on ethical principles of equity and technical knowledge (Matesanz, 2003; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999; Miranda, Naya, et al., 1999; *The ONT*, n.d.). It functions as an operational technical unit whose main objective is the promotion of altruistic donation and whose sole purpose is to increase the likelihood of a transplant for all Spanish citizens who need it. Its role therefore, goes beyond organ sharing as it

provides support to the entire network of procurement hospitals by dealing with organ transportation and sharing and maintaining the waiting lists and transplant registries.

The central office acts as the link with the Spanish department of health and ensures the flow of information to the more technical units. This office acts as the chair for the Transplantation Commission of the Health Inter-Territorial Council which is in charge of all decision-making concerning donation and transplantation activities. In addition, it is in charge of generating and updating statistics and reports and elaborates studies around organ donation and transplantation. It also runs a 24-hour hotline, promotes education, diffuses information to the public and cooperates with international agencies to further the success of organ donation and transplantation. The central office is manned by the national coordinator who is nominated and paid by the national authorities and assisted by a team of healthcare professionals and administrative staff.

#### 3.2.2.2. Regional (autonomous) Coordination

Coordination of organ donation follows the same decentralization as that of Spain as a country (Matesanz & Dominguez-Gil, 2007; *The ONT*, n.d.). Therefore, coordinators are nominated and paid for by the 17 autonomous regions to provide coordination at each regional level. The regional coordinator is seen as an interface between the health administration and the transplant professionals.

#### 3.2.2.3. Local (hospital) Coordination

Transplant coordinators are considered the cornerstone of the Spanish donation and transplantation system as they are in charge of ensuring coordination and enhancing donation at the hospital level (Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999). As such, they are fully invested in the donor recruitment effort and are accountable for the results. Transplant coordinators are mostly ICU physicians and, to a lesser extent, nephrologists who dedicate part of their time to transplant related activities. They work in a transplant hospital, are appointed by and report to the medical director, are completely independent of the transplant team and are functionally linked to the regional and national coordinators. Their main objective is organ procurement for deceased donation but they are also involved in promoting organ donation and responding to the media, implementing training and educational programs, managing resources, conducting research and undertaking various administrative tasks. This arrangement works well in a country like Spain where there is a high level of doctors with low income pay. The prospect of additional payments for part-time work as a transplant coordinator acts as a welcome incentive. Nurses also play an important role as both support for the intensivist coordinator or as transplant coordinators themselves. Spain has invested considerable efforts in training healthcare professionals and setting up transplant coordination as a discipline.

# 3.2.2.4. Quality assurance

The Spanish Quality Assurance Program in the Deceased Donation process was established by the ONT in 1989 with the aim of monitoring and evaluating the process

by estimating the capacity for deceased donation and analyzing the reasons for losing potential donors (Matesanz, 2003; Matesanz & Dominguez-Gil, 2007; Rosa et al., 2012; Rudge et al., 2012). Intended as a tool for identifying areas for improvement, the program consists of both internal and external evaluations.

The internal evaluation is performed by the transplant coordinator and consists of a review of medical records of deaths that occurred in the critical care unit in an attempt to identify potential donors that were missed by the system. The transplant coordinator looks for lost opportunities for actual donors and reasons why specific cases where not referred. The collected information is managed by the ONT which builds indicators for the overall performance of the process and identifies specific areas for improvement. Information is also shared with specific hospitals when necessary.

External audits are performed at the request of regional transplant coordinators and are developed in the form of a peer review process intended in the spirit of collaboration and sharing of best practices and experiences in an effort to learn and improve. The review is carried out by 2 or 3 critical care physicians with at least 5 years of experience as a transplant coordinator and who have previously worked in an audited hospital and received training in the quality assurance program's methodology. Similarly, to the internal evaluation, the external evaluation aims to evaluate performance of the donation process through the identification of cases that were not referred, the analysis of the reasons for this omission and highlighting areas for improvement. Moreover, the external review allows for the evaluation of the internal evaluation. This evaluation culminates in findings and recommendations that are summarized in a report that is

shared with the ONT, the hospital coordinators, the regional coordinator and the hospital director.

#### 3.2.2.5. Professionalization of organ donation

One of the cornerstones of the Spanish Model was the professionalization of transplant coordination (Matesanz, 2003; Matesanz, Domínguez-Gil, et al., 2011; Paez et al., 2009; Rudge et al., 2012). The Spanish central health administration has financed and directed considerable efforts towards the education and training of transplant coordinators. In 1991, the transplant procurement management (TPM) project was started as a specialized professional training program under the auspices of the University of Barcelona and with technical and financial support from the ONT (Manyalich et al., 2011) with the intent of producing well-trained transplant coordinators. Offerings under this program range from several master's degrees, postgraduate diplomas, and specialization certificates as well as national training courses, fellowship programs and e-learning modules all specifically geared towards providing participants with the necessary knowledge and skills necessary to the various steps in the organ donation process including donor detection and management, legal and organizational aspects, resource management and how to approach the family for consent. The intent is to create a pool of professionals capable of ensuring that organs are effectively procured, preserved, and allocated in a process characterized by transparency and high quality.

#### 3.2.2.6. Relationship with the media

In the interest of promoting transparency and enhancing societal trust, much attention was devoted to working closely with the media to keep direct communication channels open, ensure adequate handling of information and proper management of adverse publicity (Matesanz, 2003; Matesanz, Domínguez-Gil, et al., 2011; Miranda, Lucas, et al., 1999). Efforts include putting in place a consistent communication policy, manning a 24-hour hotline and arranging regular meetings with journalists and community leaders and offer communication training courses for regional and local coordinators.

#### 3.2.2.7. Legislation and Policy

Prior to 1979, donation and transplantation activities in Spain, although backed by scientific protocols, lacked the official legal support and were left to the discretion of individual judges (*History of the ONT*, n.d.). The need for legislative support led to the enactment of Law 30/1979 and Royal Decree 426/1980 which provided the Spanish system with the appropriate legal basis to support the organ donation and transplantation process. Although subsequently revised, the core elements of this law are still in effect to this day.

Approved by Parliament in 1979, the transplant legislation in Spain is similar to that found in other western countries. It offers an adequate legal background that includes the definition, certification and diagnosis of brain death, the importance of informed consent, the anonymity of the donor, the application of impartial medical criteria in the allocation of organs and the lack of compensation for donated and grafted organs

(*History of the ONT*, n.d.; Matesanz, 2003; Miranda, Lucas, et al., 1999). Of particular interest, the criteria for defining brain death are still based on the original definitions of the 70s and were purposely left ambiguous in terms of technological advancements (Matesanz, 1998). The law was also conservative in the requirement of three physicians to diagnose or confirm brain death. Although Spain follows an opt-out system and consent is presumed by law, consent is still solicited from the next-of-kin whose wishes are respected before proceeding with donation.

Article 4 of the European Parliament Directive 2010/53EU and the July 7, 2010 Council on quality and safety standards for human organs intended for transplantation, stipulates that Member States should have a quality and safety framework with a series of minimum requirements including the adoption and implementation of operating procedures (*Programa Marco de Calidad y Seguridad - Todos Los Documentos*, n.d.). In accordance, Royal Decree 1723/2012, tasked the ONT in cooperation with the Autonomous Communities with the establishment of the Framework Program for Quality and Safety. The subsequent legislative development order SSI/2396/2014, set the content and organization of the Framework Program as well as the foundations for its development as an integrated and regularly updated set of measures aimed at continuously improving the process of organ donation and transplantation by increasing its effectiveness and efficiency and reducing its risks.

#### 3.2.2.8. Financial Coverage

Another important aspect of the Spanish model is hospital reimbursement which is covered by the regional administration through a budget specifically allocated for this purpose (Matesanz, Domínguez-Gil, et al., 2011; Matesanz & Dominguez-Gil, 2007). Each corresponding regional health authority develops a budget for the procurement and transplantation hospitals in its region based on the donation and transplantation activities of the previous year. Reimbursement covers all necessary resources both human and material resources that are needed to allow hospitals to develop efficient donation and transplantation programs.

#### 3.3. FRANCE

Being among the first countries to perform a kidney transplant back in 1955, France is considered one of the pioneers in organ donation and transplantation (Antoine & Legendre, 2017). Since then, the French have continued to enhance their deceased donation and transplantation rates through improved conversion rates by introducing an efficient system that allows the early identification and follow-up of potential donors. Initiatives such as the Cristal Action Program have helped in raising awareness among healthcare professionals and training them in the identification of potential donors as well as modes of communication with the next of kin. However, the increase in donation rates in France is mainly attributed to the utilization of older donors through the application of the expanded criteria for donor identification along with rigorous donor management protocols. Moreover, the numbers have also increased due to the use of donors after circulatory death (DCD) (Antoine & Legendre, 2017).

Organ donation in France is considered an act of solidarity that is guided by three main ethical principles as elaborated in the law of December 22, 1976. These include presumed consent, gratuity and anonymity (*Agence de la biomédecine*, n.d.; *Don d'organe*, n.d.; Caillé & Doucin, 2011; DGOS, 2021). In the spirit of presumed consent, all individuals are considered donors in France unless they clearly express their refusal to donate by voicing it during their lifetime. To this purpose, the French transplant agency known as the "Agence de la Biomedecine" (ABM) maintains a national refusal register where to record such cases. To avoid the temptation of organ trafficking and the preying on the vulnerable, organ donation is free. Attempts to seek any remuneration whether monetary or in kind is not allowed and heavily sanctioned. Finally, organ donation remains anonymous in that the identity of the donor is not shared with the recipient and the identity of the recipient is not shared with the family of the donor. Nevertheless, the latter can be informed about the specific tissues and organs that were recovered and the status of the transplantation efforts if they enquire.

In 2019, France had a deceased donation rate of 33.25 pmp, a living donation rate of 8.0 pmp (*IRODaT - International Registry on Organ Donation and Transplantation*, n.d.) and a transplant rate of 90.23 patients per million inhabitants (*Global Observatory on Donation and Transplantation*, n.d.) with a total of 5,901 transplants performed in that year, 62% of which were kidney transplants ("Tout savoir sur les dons," n.d.). Transplantation rates vary by department. Of the 26,116 individuals who needed a transplant in 2019, there were 17,477 still waiting and 719 who died while waiting. The

refusal rate was 30.5%. The budget for organ donation in France in 2019 was 68.8 million euros (*RAPPORT ANNUEL 2019*, n.d.).

## 3.3.1. Service Delivery and Society and Culture

Organ procurement in France, as is the case in other countries, is made possible through the use of three sources namely, from cadaveric donors, living donors and, non-heart beating donors (Antoine & Legendre, 2017; Jousset et al., 2009). The majority of the organs in France are recovered from deceased donors but in order to increase the numbers, transplantation from non-heart beating donors was legalized in 2005 and kidney transplantation from living related donors are encouraged.

#### 3.3.1.1. Deceased Donation

The process of deceased organ donation and transplantation in France is described in figure 3.8. Upon the declaration of brain death, if the deceased is not registered on the national register for donation refusals, the process of organ procurement is initialized by artificially maintaining the deceased body while tests are performed to determine the compatibility of the donor with recipients on the waiting list (*Don d'organe*, n.d.). The hospital procurement coordination team contacts the regional services of the ABM and the relatives are approached by a team consisting of the physician and paramedical team in charge of the deceased as well as the hospital procurement coordinating team. The relatives are informed, the process is explained and the team remains at the parents' disposal throughout the process which could be interrupted at any point for either medical reasons due to the degradation of the organs or emotional reasons due to any indication of refusal on the part of the deceased.

The declaration of brain death is based on the observation of three standardized medical criteria, confirmed by several encephalograms and corroborated by two separate physicians both of whom are independent from the transplant team (*Don d'organe*, n.d.; Jousset et al., 2009)

Organs are allocated using algorithms to prioritize candidates from the national priority list that are compatible and have an urgent need for one organ or are in need of multiple organs (Antoine & Legendre, 2017). In the absence of such priorities, allocation is done on the basis of a scoring mechanism. Pediatric recipients are given priority for pediatric organs.

Organ procurement can only be performed for therapeutic purposes in authorized hospitals by a specialized medico-surgical team (*Don d'organe*, n.d.; "Tout savoir sur les dons," n.d.; Jousset et al., 2009). Hospitals involved with organ procurement are authorized by the regional health agencies in consensus with the ABM (Dorent et al., 2010). These authorizations are renewed every five years. If the donor dies in an unauthorized hospital, then the deceased is immediately medically transported to one that is (*Don d'organe*, n.d.; "Tout savoir sur les dons," n.d.). Once the required organs have been procured the body is returned to the hospital where brain death was diagnosed, at no additional cost to the relatives. Several organs may be removed based on their condition and the need. Organs are refrigerated, stored in liquid and transported by the fastest means to an authorized transplant hospital where a specialized team awaits to receive them. Transplant hospitals are authorized by recommendation of the

ABM (Dorent et al., 2010). Transplantation of organs can only occur within the public sector (*Don d'organe*, n.d.). No organ procurement can be performed without first informing the ABM (Jousset et al., 2009).

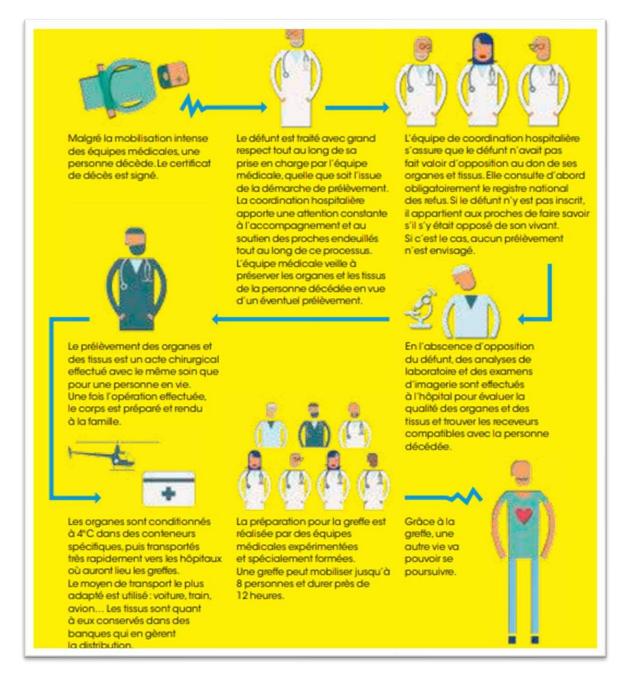


Figure 3.9: Organ donation process in France

Source: <a href="https://www.dondorganes.fr">https://www.dondorganes.fr</a>

DCD donation using a single national protocol issued by the ABM is supported in France since 2005 in a limited capacity that includes a few pilot centers (Antoine & Legendre, 2017; Caillé & Doucin, 2011; Jousset et al., 2009). According to the Maastricht classification, there are four categories of potential DCD donors namely, category I: dead on arrival, category II: unsuccessful resuscitation, category III: awaiting resuscitation and category IV: cardiac arrest in brain dead donor (Jousset et al., 2009). In France, most cases are of the first category. Moreover, patients should be between 18 and 55 years of age and have arrested due to cardiac disease, trauma, anoxia, suicide or stroke.

## 3.3.1.2. Living Donation

Since 2005, donations form living related donors are allowed in France (Antoine & Legendre, 2017; Caillé & Doucin, 2011; Jousset et al., 2009). First-, second- and third-degree relatives including spouses, parents, grandparents, siblings, children, aunts, uncles and stepparents as well as individuals who can demonstrate that they have been in a continuous relation with the recipient for the past two years are allowed to donate. However, the numbers remain low due to doubts about its success based on mortality and morbidity reports from previous experiences as well as the tedious process involved in obtaining approval. In fact, by law, living donor has to be approved by a committee consisting of a panel of five experts appointed for three years by the French Minister of Health (Jousset et al., 2009). This panel is composed of three doctors, a social scientist and a psychologist who are tasked with approving the donation after confirmation of lack of coercion and medical or psychosocial. Moreover, they are also tasked with making sure that the donor is aware of the risks and benefits involved in organ donation

and informed of the possible consequences and the availability of alternative treatments (Antoine & Legendre, 2017; Caillé & Doucin, 2011; Jousset et al., 2009). Finally, the donor must appear before the district court judge to ensure informed consent and legal status.

As with deceased donation, the ABM must be informed prior to all living donation procedures and no organs can be procured from a living minor or a living adult with mental disability (Jousset et al., 2009).

## 3.3.1.3. Society and Culture

Being stench believers in the concepts of solidarity and equality, the French have established an organ donation system with an opt out policy reinforced by a refusal register where citizens are encouraged during their lifetime to officially declare their unwillingness to donate their organs after death if that is the case ("Online Refusal Register for Organ Donation in France," 2017). It is believed that citizens in the spirit of solidarity will be unlikely to opt out of organ donation. The refusal rate, which varies by region, was around 30% on average in 2019 (*Cp\_abm\_\_bilan\_activite-Greffes\_2020.Pdf*, n.d.). Additionally, the allocation system is centralized in an effort to respect the French society's strong sense of fairness and equality (*Agence de la biomédecine*, n.d.).

## 3.3.2. Governance and Regulation

Since 1996 and based on the bioethics laws of the country, organ donation has been governed by a public agency established under the umbrella of the Ministry of Health

with the intent of overseeing all matters related to organ tissue and cell procurement and transplantation (*Agence de la biomédecine*, n.d.; Antoine & Legendre, 2017; Dorent et al., 2010; Jousset et al., 2009). First known as the *Établissement français des greffes*, with the revision of the law in 2005 it became what is now referred to as the *Agence de la Biomédecine* (ABM) (Dorent et al., 2010). The ABM is also in charge of medically assisted reproduction, ante-natal diagnosis, human genetics and embryo research (*Agence de la biomédecine*, n.d.; Jousset et al., 2009).

In general, the ABM is responsible for ensuring that the process is run ethically, in conformity with the guiding principles governing organ donation. The ABM is in charge of setting the regulations for, guaranteeing the quality and safety of and promoting the transparency in healthcare practices and patient management. To this end, the agency gathers, analyzes and disseminates information and keeps the public informed. It maintains a national database (CRISTAL) that allows the collection of data on potential and actual donors as well as information on procurement, transplant and follow-up information with the aim of documenting the process, controlling its quality and safety and furthering knowledge through research (Antoine & Legendre, 2017).

More specifically, when it comes to organ donation and transplantation, the agency, being the expert in the field, plays several roles including that of strategist, administrator and regulator as well as evaluator and quality controller (*Agence de la biomédecine*, n.d.; Dorent et al., 2010). The ABM manages both the national refusal registry and the waiting list, develops, in association with the transplant community, the rules for organ

allocation, coordinates organ donation and allocation throughout the country, organizes living donor committees, licenses hospitals and assesses the quality of the service, works continuously on improving the process and provides educational opportunities, training workshops and outreach activities (*Agence de la biomédecine*, n.d.; Antoine & Legendre, 2017; Dorent et al., 2010).

Over time and in collaboration with the professional and scientific communities, the ABM has managed to increase its expertise and knowledge both internally and externally (*Agence de la biomédecine*, n.d.; Antoine & Legendre, 2017). It has managed to create a competent healthcare task force that is experienced and knowledgeable in the daily running of the process. The ABM and healthcare task force are continuously working on improving both the regulation and the practice of the organ donation and transplantation process in France.

#### 3.3.2.1. Organization of the ABM

The ABM is organized along two main hierarchical lines of action one for medical and scientific leadership and the other for resource management. The first combines the three divisions that reflect the main missions of the ABM in terms of procurement and transplantation of organs, procurement and transplantation of hematopoietic stem cells, medically assisted reproduction, and human genetics and embryo research (*Agence de la biomédecine*, n.d.; Dorent et al., 2010). These units are in charge of developing and applying medical policies devised in collaboration with transplant team representatives.

The unit for the procurement and transplantation of organs is further subdivided into smaller units including the four regional regulatory and support services (Structure Régionale d'Appui - SRA) that are responsible for the seven zones of organ procurement and allocation (figure 3.9) and the national organ allocation service located at the main headquarters in Saint-Denis. The four SRAs work in close collaboration with the hospital procurement coordinators and transplant teams to regulate organ recovery around the clock 24 hours per day, 7 days per week. Moreover, they represent the ABM regionally by coordinating with the regional health agencies to establish networks connecting organizations involved in organ procurement and transplantation, disseminating best practices and developing public awareness. These efforts allow for the recognition of the ABM regionally, open the dialogue with the regional health agencies and other regional establishments and ensure equity in the allocation of organs. The national organ allocation service is responsible for maintaining the national refusal registry and organ waiting list as well as the distribution and allocation of organs to patients throughout the country.

By law, all strategic and budgetary decision-making are the realm of the administrative council of the ABM (Agence de la biomédecine, n.d.). The latter is composed of 37 members of diverse backgrounds that are nominated in a ministerial order by the minister of Health. The members are equally divided between representatives of the state and public administrations and qualified health professionals and staff members.

The president of the council is appointed for a period of 3 years by a presidential decree.

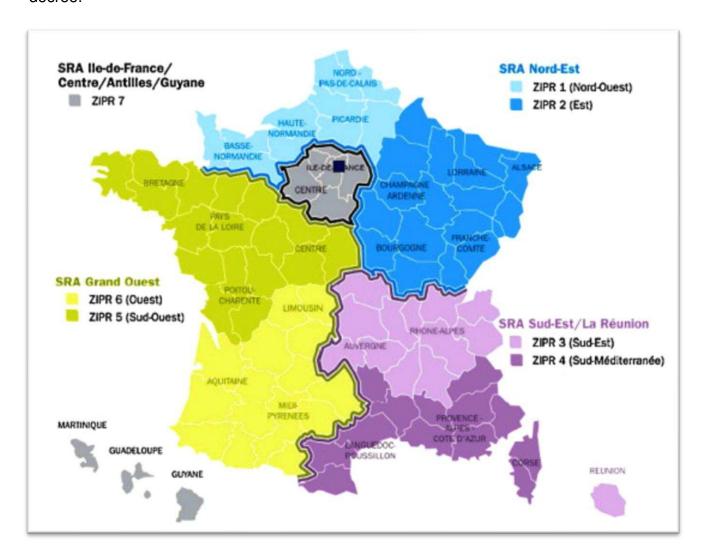


Figure 3.10: Territorial organization of the ABM

Source: http://www.agence-biomedecine.fr.

The ABM is also supported by an orientation council of 31 members representing various political institutions, the scientific communities, social and human sciences and different humanitarian associations. The council is nominated for 3 years based on ministerial orders from the ministries of health and research. Its role is to ensure the

application of ethical principles related to the field of organ donation and transplantation including the donor's and recipient's rights.

In the spirit of collaboration, the ABM encourages working groups with health professionals, other stakeholders and various public agencies and has developed a platform to allow for online consultation of concerned stakeholders. In addition, it engages in live discussions regarding new projects and plans, impacts of reforms, best practices and regulations. Figure 3.10 portrays the various bodies that the ABM collaborates with.

#### 3.3.2.2. Performance Contract

The performance contract serves as a tool to formalize the relationship of ABM with the state (*Agence de la biomédecine*, n.d.; Jousset et al., 2009). In order to valorize its contribution to public health and maximize its performance and efficiency, the ABM signs a contract with the Ministry of Health that details the expected objectives to be met by the ABM over a specified period. These include strategic actions as well as indicators for measuring follow-up and the evaluation of the activities carried out in the completion of its objectives.



Figure 3.11: The collaboration environment of the ABM

Source: https://www.agence-biomedecine.fr

# 3.3.2.3. Quality Assurance

The French system has incorporated hand in hand with the process of organ procurement and transplantation, an ongoing surveillance that consists of data collection, analysis and documentation process that allows the detection of incidents due to accidents or errors and undesirable or unexpected effects (*Agence de la biomédecine*, n.d.).

Moreover, in accordance with both the quality directive of the ABM and the duty of the establishments authorized to recover organs to provide a safe, quality service in the spirit of best practices, the ABM put in place, since 2017, a new audit system which is performed by the SRA (*Agence de la biomédecine*, n.d.). This external evaluation is exploited as a tool to support the work of hospital procurement coordination teams since it offers an opportunity to exchange on professional engagement, best practices, organizational challenges and results. It helps in devising action plans in order to improve the quality and safety of the procurement and transplantation process.

As a first step, SRAs identify, based on quantitative and qualitative data and the date of the last audit performed, hospitals that could be eligible for participation in an audit in the coming year. Next, the hospital procurement coordination team performs an auto evaluation of the organ recovery activities within the hospital based on the guidelines provided by the ABM. The evaluation is sent along with supporting documents to the ABM. The audit is then conducted by a pair of peers, a doctor and a nurse, from SRA. The audit usually takes 2 days and consists of meetings with the different stakeholders involved in the procurement process as well as site visits and document review and analysis. As a result of the audit a report is generated and shared with the hospital if the findings are contradictory to the auto evaluation. The report also suggests recommendations that are taken into consideration by the ABM and regional health agencies upon renewal of the hospital's authorization for organ donation.

In addition, since 2018, the area of organ and tissue donation has been added to the certification process of the higher authority for heath (Haute Autorité de Santé – HAS) for hospitals authorized in organ procurement (*Agence de la biomédecine*, n.d.). To this end, nine experts and five project heads from HAS have been trained by the ABM to become knowledgeable in this field. The objectives of the HAS certification visit are set by the ABM based on the recommendations of the audit.

# 3.3.2.4. Legislation and Policy

Three main laws established the process of organ procurement and transplantation in France (*Agence de la biomédecine*, n.d.; DGOS, 2021; Jousset et al., 2009). The first was the law of Caillavet (No. 76-1181) promulgated in 1976 which defined the concept of 'presumed consent' and proposed the judicial framework that served as a basis for organ procurement in France. This was later followed by the Bioethics Law in 1994 (No.94-654) and further revised in 2004 (No. 04-800), which served to establish the legal rules concerning organ donation and transplantation. The latter law also served to define the regulations for living donation. In addition, table 3.2 presents a series of legal texts that are used as reference to support organ donation and transplantation procedures in France (*Don d'organe*, n.d.).

Table 3.2: Legal texts in support of organ donation in France

Law	Purpose
Public health code: articles L1211-1 à	
L1211-9	
Public health code: article R1211-10	
Public health code: articles R1232-4-4 à	Expressing refusal for organ procurement
R1232-4-7	
Public health code: articles R1232-5 à	Automated national register for refusal of
R1232-14	organ procurement
Public health code: articles L1232-1 à	
L1232-6	
Decree of August 2, 2005	List of organs for which DCD
	procurement is authorized
Decree of October 29, 2015	Best practices relative to organ
	procurement for therapeutic purposes
Decree of August 16, 2016	Best practices relative to approaching
	relatives for organ procurement

Source: https://www.service-public.fr/particuliers/vosdroits/F183

# 3.3.2.5. Financial Coverage

The organ procurement process is financed by the hospital in which the procurement occurs. This includes conservation and restauration as well as any necessary transportation and restitution of the deceased's body (*Don d'organe*, n.d.).

#### 3.4. TURKEY

Contrary to most organ donation models in Western countries, organ donation in Turkey is generally dependent on living donors. In fact, 80% of all donation activities in Turkey are attributed to living donors (Can & Hovardaoglu, 2017).

Organ donation in Turkey began in Ankara in 1975 when the first kidney transplantation from a live donor was performed (Akbulut & Yilmaz, 2015; Karakayali & Haberal, 2005;

Usul et al., 2020). This first attempt was followed a few years later in 1978 with the first kidney transplantation from a deceased donor. However, since there was no law for deceased donor utilization in Turkey at the time, this effort was the result of collaborations with international networks and organizations such as the South Eastern Organ Procurement Foundation in Richmond Virginia and the Eurotransplant Foundation in the Netherlands. In fact, the latter supplied the organ used for the transplantation (Akbulut & Yilmaz, 2015; Haberal et al., 2019; Karakayali & Haberal, 2005). It is only a year later in 1979 that the first Turkish national law for harvesting, storage, grafting, and transplantation, law 2238 was enacted (Akbulut & Yilmaz, 2015; Karakayali & Haberal, 2005). This paved the way for the first kidney transplant from a local deceased donor that same year while the first cadaveric liver transplant took place in 1988 and the first living-related liver transplantation in 1990 (Karakayali & Haberal, 2005; Usul et al., 2020).

In 2019, Turkey had a deceased donation rate of 7.54 pmp, a living donation rate of 53.02 pmp (*IRODaT - International Registry on Organ Donation and Transplantation*, n.d.) and a transplant rate of 69.43 patients per million inhabitants (*Global Observatory on Donation and Transplantation*, n.d.) with a total of 5,763 transplants performed in that year, 67% of which were kidney transplants. That same year there were 26,783 patients registered on the waiting list (*TTDISKDS PUBLIC*, n.d.). By 2019, over a period of 40 years, a total of 38477 kidney transplants (8278 deceased, 30199 living); 14185 livers (4187 deceased, 9998 living); 1048 hearts; and 195 pancreas transplants have been performed in the country (Haberal et al., 2019). Although transplantation on

foreign nationals has been observed in Turkey since 2011, the majority of transplantations are performed on Turkish nationals (Diniz et al., 2019).

#### 3.4.1. Service Delivery and Society and Culture

There are 99 licensed public and private transplant centers mostly limited to solid organ kidney transplant and 58 tissue typing laboratories distributed among 31 provinces in Turkey (Diniz et al., 2019; *TTDISKDS PUBLIC*, n.d.; Usul et al., 2020). Despite the distribution of centers over nine coordination regions in Turkey, the majority are affiliated to the Istanbul region where there are 43 centers. There is also a concentration of centers in some cities. For example, in the Ankara region, 14 of the 15 centers are found in Ankara. As a result, organ recipients are sometimes found in locations that are far removed from the donation center (Usul et al., 2020). Therefore, one of the main problems faced by organ donation in Turkey is the need for rapid transportation of organs and sometimes surgeons if the latter is not available in the donation center.

Although both living and deceased donation are available in Turkey and despite the legislation, and efforts expanded in developing a deceased donation process, the main focus is on living donors that account for 80% of organ donation activities in the country (Can & Hovardaoglu, 2017). In Turkey, the transplantation of organs namely, kidney, skin, liver, heart, lungs, pancreas, small intestine and tissues such as bone, bone marrow and cornea is permitted (Alan & Kurt, 2019).

## 3.4.1.1. Living Organ Donation

Living donation which appears to be religiously more appealing and therefore ethically more acceptable to the Turkish population, has in general a higher success rate than that of the deceased donation alternative (Alan & Kurt, 2019). By law, mentally competent adults (over 18) who have expressed their will verbally and have given consent in writing can become living donors of organs and tissues as long as the act is done altruistically with no material gain, financially or otherwise (*2238 Organ Transplantation Law*, n.d.; Avci, 2018; Ertin et al., 2010; Karakayali & Haberal, 2005). The consent document must be signed by the donor, approved by a physician and witnessed by at least two people. The specifics of becoming a living donor are further detailed by the Directives on Organ and Tissue Services.

In Turkey both living-related and unrelated organ donation are possible (Avci, 2018). Living-related donation is allowed upon compatibility of blood and tissue type for blood relatives (up to fourth degree), relatives in law and spouses living together for more than two years (Alan & Kurt, 2019; Avci, 2018). For living-unrelated donation, both the donor and recipient must apply to the ethics committee approval (Avci, 2018). The role of the ethics committee is to investigate possible illegal or unethical transactions between the donor and recipient and grant its authorization for the donation and subsequent transplantation.

#### 3.4.1.2. Deceased Organ Donation

Deceased organ donation in Turkey is only allowed in the case of a brain death (Alan & Kurt, 2019; Can & Hovardaoglu, 2017) that is confirmed in the ICU (Alan & Kurt, 2019). By law, organs from donors whose death happened in other instances such as those occurring at home, at the site of the accident or on the way to the hospital, are not acceptable for use in the donation process (*2238 Organ Transplantation Law*, n.d.; Alan & Kurt, 2019).

Brain death should be unanimously declared by a committee of four physicians consisting of a cardiologist, a neurosurgeon, a neurologist and an anesthesiologist (2238 Organ Transplantation Law, n.d.; Karakayali & Haberal, 2005). The assessment is made based on a physical examination as well as radiology and laboratory tests (Alan & Kurt, 2019). To make it official and allow the harvesting of organs, the brain death declaration should be accompanied by a certificate. Once brain death is confirmed, the primary doctor is tasked with informing the family after which they are approached by the transplant coordinator for the possibility of organ harvesting (Alan & Kurt, 2019; Can & Hovardaoglu, 2017).

Individuals can express their will to donate their organs after death by filling out an application form on the E-nabiz platform available on the website of the Turkish Ministry of Health (Alan & Kurt, 2019; *TR Ministry of Health*, n.d.). Donation cards can be obtained from the local health authorities, organ donation units or family physicians and should be carried at all times (Alan & Kurt, 2019). Individuals can specify which organs

they wish to donate and are free to destroy the card or inform their family if they change their minds about the donation act. In any case, the donation card is not sufficient on its own as organs will not be recovered from a deceased donor without the consent of the family (Alan & Kurt, 2019; Avci, 2018; Can & Hovardaoglu, 2017; Karakayali & Haberal, 2005). However, in the case of an emergency, if a death occurs naturally or as a result of an accident, undamaged organs may be procured and transplanted without consent in the absence of the next of kin (2238 Organ Transplantation Law, n.d.; Avci, 2018).

Organ allocation is done centrally by the National Organ and Tissue Transplantation
Coordination System based on blood group compatibility as well as medical urgency
and physical distance (Alan & Kurt, 2019; Ertin et al., 2010). Using established criteria
for organ sharing and a committee consisting of the Regional Coordination Centers, the
National Coordination Center and the Ministry of Health is tasked with the responsibility
of fairly matching donors to recipients based on a scoring system that incorporates all
the necessary criteria. Therefore, when a cadaveric organ becomes available it is
immediately allocated to the patient with the highest score and sent to the hospital
caring for him. Priority is given to urgent cases within the same region.

Waiting lists by type of organ are developed by the transplantation centers based on formats established by the Ministry of Health following recommendation from the Scientific Council Institution. The transplant centers inform the corresponding Regional Coordination Centers of their needs in terms of organs and tissues and can even contact the National Coordination Center in case of emergencies. Organ transplantation

is carried out by surgical teams that ensure that the body integrity is preserved upon returning it to the parents.

#### 3.4.1.3. Society and Culture

Turkey has adopted an opt-in system for organ donation thus allowing its citizens to voice their will to become donors while forbidding, in most cases, donation where there is no consent (*2238 Organ Transplantation Law*, n.d.).Yet, although studies in Turkey have shown that two thirds of the population (67%) appear to have positive attitudes towards organ donation (Akbulut et al., 2020; Can & Hovardaoglu, 2017), only 0.5% of the population have organ donor cards and whereas three quarters of the population claim that they would donate their relative's organs, the actual donation rate is only 24% (Can & Hovardaoglu, 2017). This is mostly explained by lack of public awareness, distrust in the health system, the diagnosis of brain death and the fairness of the organ allocation system as well as religion, cultural values and the negative attitude of health professionals (Akbulut et al., 2020; Akbulut & Yilmaz, 2015; Can & Hovardaoglu, 2017; Gurler & Hancer, 2020; Haberal et al., 2019; Ozsoy et al., 2021).

These factors also explain the high prevalence of living donation (Akbulut & Yilmaz, 2015; Avci, 2018) despite international directives to decrease living donation and increase deceased donation. Although organ donation in Turkey is condoned by religion and the supreme fatwa board of the Presidency of Religious Affairs, which is the Religious Affairs Supreme Council, has decided that organ and tissue transplantation is permissible under certain conditions and has reinforced this by referring to the specific

statements and verses (Aykas et al., 2015), the population continues to invoke religious objections and express fear for deceased organ transplantation. To counter these barriers, living donation continues to be highly encouraged in Turkey which elicits concerns over organ trafficking (Avci, 2018).

The Turkish media, including newspapers, does not help as it appears not to have adequate information on transplantation (Göbekli et al., 2019). Published material on organ donation is sparse, but it is interesting to note that what is available is supportive and focuses mostly on partnership and giving a life from one person to another.

# 3.4.2. Governance and Regulation

Most of the early efforts for the establishment of organ donation in Turkey were based on individual or group initiatives of professionals in the field (Haberal et al., 2019; Karakayali & Haberal, 2005; Usul et al., 2020). These include the first transplantations performed, the contact with international networks, the formation of the national organsharing program and the creation of organizations and societies including the Middle East Society for Organ Transplantation (MESOT). Moreover, these professionals were actively engaged in providing education to the public on the benefits and social responsibilities of organ donation as well as working diligently on convincing politically influential individuals such as members of Parliament, officials in the Department of Religious Affairs, the Ministry of Health, and other governmental institutions of the importance of organ donation and its lifesaving role.

As of 2001, the process of organ donation and transplantation in Turkey is controlled by the Ministry of Health and all information relative to transplant numbers, donors, centers and waiting lists can be found on the website of the ministry (Usul et al., 2020). The organ transplantation policy developed by the Ministry of Health was adopted as a national policy and the Department of Tissue, Organ Transplantation and Dialysis Services was established (Akbulut & Yilmaz, 2015; *TTDISKDS PUBLIC*, n.d.) within the General Directorate for Treatment Services of the Ministry of Health. This unit has developed and maintains online the Turkish Organ and Tissue Information System that collects data on all individuals who have been transplanted or are on the waiting list. The system is accessible through a login system to all concerned stakeholders.

Although a national organ sharing program was initiated in 1989 to coordinate organ donation, enhance collaboration between transplant centers and ensure the fair allocation of organs at the national level (Karakayali & Haberal, 2005), since 2001 the Ministry of Health established the National Organ and Tissue Transplantation Coordination System to take over this role and work on promoting transplant activities (Akbulut & Yilmaz, 2015; Can & Hovardaoglu, 2017; Ertin et al., 2010; Karakayali & Haberal, 2005). In order to guarantee its proper functioning, a directive was proposed and it received ministerial approval in 2008 (Akbulut & Yilmaz, 2015). The coordination system which is designed along the lines of the Spanish system to allow coordination at three levels namely national, regional and hospital (Ertin et al., 2010). Therefore, using this model, donors are reported by hospital coordinators to the regional coordination centers and then to the national coordinating center.

Today, all resources related to organ donation in Turkey have been consolidated in the National Coordination Center (Akbulut & Yilmaz, 2015; Can & Hovardaoglu, 2017; Haberal et al., 2019; Karakayali & Haberal, 2005) which oversees nine regional coordination centers that are in charge of all the transplant centers in the country (Akbulut & Yilmaz, 2015; Can & Hovardaoglu, 2017). The nine regional centers were established in nine of the larger provinces chosen based on geographical regions, population distribution and transportation considerations. All other provinces are dependent based on their geographical proximity on one of these nine centers. Hospital coordinators are mostly physicians and/or nurses but in some cases could be biologists or other healthcare professionals (Ertin et al., 2010). A hospital could have a single coordinator or a team of coordinators consisting of two or more physicians and nurses. The hospitals that do not have a dedicated coordinator get assigned a coordinator from a different hospital at the time the donation is planned.

# 3.4.2.1. Legislation and Policy

The Turkish law 2238 on the Harvesting, Storage, Grafting, and Transplantation of Organs and Tissues which was enacted in 1979 and amended in 1982 by law 2594 governs all aspects of organ transplantation in Turkey (Akbulut & Yilmaz, 2015; Ertin et al., 2010; Haberal et al., 2019; Karakayali & Haberal, 2005). The law is composed of fourteen articles divided in four chapters namely, general provisions, harvesting of organs/tissues from living donors, harvesting of organs/tissues from deceased donors, and punitive articles (*2238 Organ Transplantation Law*, n.d.; Akbulut & Yilmaz, 2015; Karakayali & Haberal, 2005). This law is supported by the Turkish Criminal Code which

bans organ trafficking by prohibiting all activities involving the buying or selling organs or tissues in any form and imposes punishments on all parties who engage in such illegal activities (Avci, 2018; *Legislationline*, n.d.). However, the law also provides the judge with some leeway in reducing the sentence in case of difficult social or economic situations.

In addition, there are a number of other legal documents that help in the regulation of organ donation (*Legal Regulations | Organ Transplantation Foundation of Turkey - Let Life Continue*, n.d.). These include regulatory texts such as Regulations on Quality and Safety of Human Tissues and Cells Related Centers and Organ and Tissue Transplantation Services Regulation, circulars (i.e. National Transplant Information System), directives (i.e. National Organ and Tissue Transplant Coordination System Directive) and Religious Affairs Supreme Council Decisions (i.e. Decision of the Supreme Council of Religious Affairs on Organ Transplantation and Organ Donation).

#### 3.4.2.2. Financial Coverage

The financial burden of organ donation is on the state (Ertin et al., 2010). Details on coverage logistics are found in the document on Price Tariff Procedures and Principles (*EK-1-Fiyat-Tarifeleri-Usul-ve-Esaslari.Pdf*, n.d.).

# 3.5. PERFORMANCE MANAGEMENT CONSIDERATIONS IN DIFFERENT ORGAN DONATION AND TRANSPLANTATION MODELS

It is clear from what has transpired above that organ donation and transplantation rates vary from country to country. With the aim of achieving a state of self-sufficiency, countries have devised individual governance systems that allow them to optimize their legislation, regulatory policies, resources and cultural contexts (Delmonico et al., 2011). Yet, the three components of the Mikkelsen-Lopez et al. (2011) governance framework namely, service delivery, governance and society are well represented in all contexts.

In fact, the donation and transplantation processes described for the four countries consists of three main toolboxes namely, a policy or governance toolbox which comprises strategies for allocation of organs, networking among different entities and sharing of evidence and information, a hospital or service delivery toolbox which focuses on skill enhancing and team building and collaboration within the hospital and finally a citizenship toolbox to promote awareness and trust from a medical and ethical perspective. To date, most of the research has focused on analyzing the core of the process which is the clinical pathway. This aspect has been well documented and the literature abounds with articles and indicators measuring performance in that respect. It is clear however, that more work is needed with regards to the governance, regulation and interorganizational collaboration aspects. It is interesting to note that although these elements are well developed in most systems they are not highlighted in research on

organ donation and transplantation but instead are relegated to the realm of progress reports that are used for planning purposes.

Of particular interest in these systems is the type of regulatory agency proposed and the essence of the collaboration between the public and private sectors (Kazemeyni et al., 2009). In the US, for example, organ donation and transplantation is managed in the private sector by the United Network for Organ Sharing (UNOS) while in Spain and France they are run by governmental agencies such as the National Transplant Organization (ONT) and the Agency of Biomedicine respectively. In Turkey, like in Spain and France, organ donation is regulated in the public sector but not as a public agency but as a department within the Ministry of Health. These differences stem from the differences in the healthcare systems, political ideologies and cultural values. A PPP-governance mechanism seems to be the model of choice in private healthcare systems whereas public agencies or Units within the Ministry regulate the organ donation process in public healthcare systems.

It is also clear that management plays a central role in all the models reviewed in this chapter. Indeed, regardless of the particular system adopted, the organ donation, procurement and transplantation process can be drawn as a continuum of collaboration that starts with the government, moves to the hospital and ends in society (Triassi et al., 2014). This can then be thought of as a production path with an opportunity of improvement at every step. In fact, to maximize supply and quality, one must analyze every step in the path and identify the appropriate organizational toolbox that enhances

it. Therefore, in an attempt to position organ donation and transplantation within a performance management perspective, the performance management components of the organ donation and transplantation models described in this chapter will now be highlighted using the PMSs framework proposed by Ferreira and Otley (2009).

Information on the performance management of the four models of organ donation described above was reconstituted from the detailed information compiled on each country. The PMSs framework enabled the structuring and organization of collected information into meaningful categories that could be used to formulate an overall view of an organization's strategies and assess whether they were effectively implemented (Ferreira & Otley, 2009). The results of this analysis are summarized in table 3.3 which shows that in general, countries have a clearly stated mission and vision for organ donation and transplantation, a structured organization and detailed strategic plans that enable them to define success factors, set targets and assess performance indicators.

The four countries share the vision of increasing donation and transplantation rates and improving their services. The structure of the organization is more fragmented for the US and more centralized for Turkey. Strategic planning in the US is done by a private organization for a 3-year period while in Spain, France and Turkey it is a ministerial plan proposed in collaboration with autonomous communities and SRA for Spain and France respectively. Whereas in Spain and France this consists of a plan for organ donation only, it is not clear whether in Turkey there is a separate plan per unit within the Ministry or only a general plan for the Ministry as a whole with performance indicators for each

unit. All four countries seem to have similar key success factors but not necessarily the same performance indicators. Spain and France seem to have more ambitious targets. Turkey being regulated by a unit within the Ministry of Health appeared to be more restricted by the Ministry's objectives. All four countries have different performance evaluation mechanisms but it would appear that Spain and France use performance management more collaboratively for the purposes of learning and improving whereas for the US and Turkey it is more of a regulatory mechanism. The reward system is not clear for Spain and Turkey. Spain is the only country that does not appear to have a well-developed online platform.

Results of the analysis on performance management systems showed variations based on affiliation of care (public or private), fragmentation of the healthcare system, level of independence of the regulator, plurality of decision-making as well as political and social ideologies. The next chapter extends the analysis to the Lebanese organ donation and transplantation system for an in-depth analysis of its governance in a fragmented and fragile context fraught with political and economic instability, strong party and religious affiliations, a weak public health sector and fragmented service delivery and characterized by a society with individualistic tendencies, relational and clan domination and cultural diversity. Questions that guide the analysis in the next chapter revolve around "What mode of governance and regulation will work best in more fragmented and fragile contexts?", "What elements of the PMSs framework are implemented in a fragmented fragile context?"

Table 3.3: Different organ donation and transplantation systems through the lens of the PMSs framework

PMSs components	Countries								
	USA	Spain	France	Turkey					
1. Vision & Mission	<ul> <li>Maximize organ supply</li> <li>Ensure accessible effective and safe care</li> <li>Allocate organs equitably</li> <li>Promote public trust</li> </ul>	Coordination of donation, recovery, preservation, distribution, exchange, and transplantation of organs and tissues throughout the whole Spanish Health Care System	<ul> <li>Procurement and transplantation of organs</li> <li>Procurement and transplantation of hematopoietic¹ stem cells</li> <li>Medically assisted reproduction, and human genetics and embryo research</li> </ul>	<ul> <li>Increase the rate of organ donation within an effective, accessible and sustainable system</li> <li>Improve transplant services and provide a second chance for people in need of organ transplantation.</li> </ul>					
2. Key success factors (KSFs)	<ul> <li>Increase the number of transplants</li> <li>Provide equity in access to transplants</li> <li>Improve waitlisted patient, living donor, and transplant recipient outcomes</li> <li>Promote living donor and transplant recipient safety</li> <li>Promote the efficient management of the OPTN</li> </ul>	<ul> <li>Increase the availability of organs</li> <li>Increase access to transplantation services</li> <li>Optimize the quality and security of the transplantation process</li> <li>Establish a public, integrated, robust and secure information system</li> <li>Promote sustainability of organ donation and transplantation</li> <li>Reinforce the discourse against organ tourism and trafficking and other ethical issues</li> </ul>	<ul> <li>Improve conversion rates</li> <li>Improve access to national waiting list and develop organ transplantation</li> <li>Promote transplantation for living donors</li> <li>Develop tissue donation and transplantation</li> <li>Reinforce the evaluation of organ procurement activities and the governance of data</li> <li>Improve the quality and security of organ donation and transplantation practices</li> <li>Optimize financing mechanisms</li> <li>Support education, training and research related to organ donation</li> </ul>	transplantation.  Promote organ donation Not clearly defined for organ donation & transplantation specifically (Diagnostic, curative & rehabilitative healthcare services, quality of care, capacity speed & quality of services, specialized care, awareness)					

<sup>1</sup> An immature cell that can develop into all types of blood cells, including white blood cells, red blood cells, and platelets. Hematopoietic stem cells are found in the peripheral blood and the bone marrow.

			Improve communication to mobilize the public and health professionals	
3. Organization structure	<ul> <li>DoT within HHS -         overseer</li> <li>OPTN - PPP - board of         directors &amp; committees</li> <li>UNOS &amp; OPOs - non         profit organizations</li> </ul>	<ul> <li>ONT - public agency in charge of coordination and oversight of donation, procurement, and transplantation activities</li> <li>Decentralized donor coordination at 3 levels: national, regional &amp; local</li> </ul>	<ul> <li>ABM – public agency that oversees all matters related to organ tissue and cell procurement and transplantation</li> <li>Administrative/orientation council</li> <li>SRA – 4 regional regulatory support services</li> <li>Hospital procurement coordinators &amp; transplant teams</li> <li>Healthcare task force</li> </ul>	<ul> <li>Department of Tissue, Organ Transplantation and Dialysis Services within Ministry of Health</li> <li>National Organ and Tissue Transplantation Coordination System with coordination at 3 levels</li> </ul>
4. Strategies & plans	3-year strategic plan adopted by the Board of Directors that maintains the balance between high level community goals and specific policy projects set by committees	<ul> <li>A strategic 4-year plan for organ donation and transplantation</li> <li>National 3-year plan for tissue donation</li> </ul>	4-year ministerial plan for each mission	<ul> <li>5-year strategic plan for the Ministry of Health (organ donation and transplantation falls within)</li> </ul>
5. Key performance measures (KPMs)	<ul> <li>Conversion rates</li> <li>Time to transplantation</li> <li>Utilization rate by type of donors</li> <li>Equity in access measured by UNOS methodology</li> <li>Volunteer workforce</li> <li>Participation in OPTN of public comment period</li> <li>Waitlist mortality</li> <li>1 and 5-years graft survival rates</li> </ul>	<ul> <li>Conversion rates</li> <li>Donation and transplantation activities by type and organ</li> <li>Number of &amp; reasons for missed opportunities</li> <li>Highlighting areas for improvement</li> <li>Measures of effectiveness, efficiency &amp; risk</li> <li>Audit report</li> <li>SWOT analysis</li> </ul>	<ul> <li>Conversion rates</li> <li>Donation and transplantation activities by type and organ</li> <li>Detection of incidents</li> <li>Audit report</li> </ul>	<ul> <li>Conversion rates</li> <li>Number of kidney transplantations</li> <li>Number of people on the waiting list</li> <li>Number of donor cards</li> <li>Relevant key performance indicators were defined but not clearly listed</li> </ul>

	<ul> <li>Percent of positive member feedback</li> <li>Number of self-reported events</li> <li>Number of referrals for broader community education/communication or OPTN review committee</li> </ul>			
6. Target setting	Set in the 3 year plan as improvements in KPMs relative to previous years (increase/decrease)	Set in the 4-year plan (e.g.: 50 donors PMP by 2022 in all the autonomous communities with more than 5,500 solid organ transplants with 9 procedures PMP from living donors)	Objective and ambitious targets clearly stated in 4-year ministerial plan to support collective action (e.g.: between 1643 & 2084 organs from deceased donors and 6760 and 8528 transplants by 2026; 65 healthcare establishments applying the Maastricht protocol III & 15% transplants using said protocol by 2026; 20% kidney transplants from living donors)	Set in the 4-year strategic plan for the Ministry of Health (e.g.: rate of successful kidney transplants 97%)
7. Performance evaluation	<ul> <li>UNOS conduct routine evaluations to ensure member compliance with the requirements</li> <li>CMS certification of OPOs every 4 years</li> </ul>	<ul> <li>Quality assurance program</li> <li>Internal evaluation</li> <li>External audit/ Peer review</li> </ul>	<ul><li>Performance contract</li><li>Surveillance</li><li>Auto-evaluation</li><li>Audit</li><li>HAS certification</li></ul>	<ul> <li>Monitoring and evaluation framework</li> <li>Balance Scorecard System</li> <li>Score Performance Assessment System</li> </ul>
8. Rewards system	Recertification     Payment for services	Best practices	<ul> <li>Renew certification of hospitals authorized for organ donation</li> <li>Experience and best practices</li> </ul>	Not mentioned
9. Information flows, systems & networks	<ul> <li>SRTR provides evidence- based results to HHS for use in formulating policies, evaluating</li> </ul>	multiple registries or Information Systems coexist	CRISTAL – national database for the collection of data on potential and actual	Turkish Organ and Tissue Information System

	system performance, performing economic analysis and reporting to Congress  UNOS  OPTN public comment platform		donors, procurement, transplant and follow-up information • Online/live discussion platforms		
10. PMSs use	Diagnostic	Diagnostic & interactive	Diagnostic & interactive	Diagnostic	
11. PMSs change	<ul> <li>Change based on old &amp; new targets set in strategic plans</li> </ul>	<ul><li>Identify areas for improvements</li><li>Continuously evolving</li></ul>	<ul> <li>Based on evidence and findings presented by various stakeholders prior to setting plan</li> </ul>	<ul><li>Based on recommendations</li><li>Regular reporting</li></ul>	

Source: author's compilation

# CHAPTER 4: THE LEBANESE SYSTEM OF ORGAN DONATION AND TRANSPLANTATION: AN ANALYSIS OF GOVERNANCE ISSUES

This chapter contains the findings of the in-depth case study on organ donation and transplantation in Lebanon as an emblematic case of a fragmented healthcare system in a fragile context. The chapter provides a detailed description of the Lebanese system of organ donation and transplantation starting with a historical overview and ending with its challenges, the most critical being its governance. After presenting a brief history of its development the chapter will continue to demonstrate the challenges of the Lebanese organ donation and transplantation system through narration, rich, thick description and verbatim accounts, using the three levels of the Mikkelsen-Lopez et al. (2011) governance framework namely, service delivery, governance and society. Service delivery will include details pertaining to the three arms of an organ donation and transplantation model: living donation, deceased procurement and transplantation activities. Governance will focus on the creation of NOD-Lb, its regulatory role and the collaborative governance it enjoys with the MoPH. Finally, society will present a brief overview of the attitudes towards organ donation and transplantation. These sections will be followed by a summary of quantitative and qualitative performance indicators as well as an analysis of performance management using the PMSs framework, before expanding on the challenges with organ donation as perceived by the regulatory body and an analysis of these issues and problems from a governance perspective. The chapter will conclude with a comparison of the governance of organ donation and transplantation in Lebanon, USA, Spain, France and Turkey.

# 4.1. ORGAN DONATION AND TRANSPLANTATION IN LEBANON: HISTORY AND LEGISLATION

Organ donation started in Lebanon in 1972, with two kidney transplantations from living related donors (LRD) performed at two private hospitals. In 1983, the donation and transplantation law was promulgated marking the first official attempt to regulate the donation and transplantation process in Lebanon. The Lebanese law No 109/1983 consisted of eight articles that legalized the "donation of human tissues and organs for medical and scientific purposes". It highlighted the characteristics of the donors and recipients and emphasized the medical and noncommercial aspects of the donation act. It also allowed for donation from both live and deceased donors. Its practical applications decree No 1442/1984 followed a year later and consisted of seventeen articles intended to regulate the implementation of the law. Its articles defined brain death, provided guidelines for its diagnosis and specified the conditions for establishing a renal transplant unit. The latter included specifications on space, equipment, human resources and other health services such as labs and pharmacies. The following year (1985) witnessed the opening of the first transplantation unit in the country (center 1). Since then, the number of solid transplant units have increased to eighteen including one lung, two liver, five cardiac and ten kidney transplant centers three of which closed due to lack of funds, change of ownership or ethical considerations. In addition, there are eye banks but only one, the National Eye Bank Quarantina, is continuously functional. The other eye banks are managed by NGOs. In 2006, the first Lebanese Human Tissue Bank, operated based on international and safety and traceability standards, was established at Saint Joseph University of Beirut.

In 1990 the first kidney transplant from a deceased donor (DD) was performed. It led around a year later to the establishment of the first association for deceased organ donation in Lebanon.

In order to benefit from the lessons learned by the Spanish experience, Lebanon joined the SEUSA (Spain, Europe and USA) program at the end of 2009. The SEUSA program is a modular concept, easily adapted to local needs, that combines the best practices of the Spanish, European and American organ donation systems (Manyalich, 2013). The experience in Lebanon is listed on the DTI website as one of their success stories showing an increase in the number of donors from 0 in 2009 to 10 in 2012 as well as an increase in potential donor alerts, from 116 in the years prior to the start of the project to an average of 1500 alerts during the time of the project (2010-2012) (*Consultancy in Organ Donation | TPM – DTI Foundation*, n.d.).

During the first year of its inception (2010), the SEUSA program was implemented and monitored in fifteen hospitals in Lebanon. By the end of that first year, the program registered 1501 alerts for potential donors of which 139 had severe neurological damage (SND) and 65 were diagnosed as brain deaths. There were 2 organ and 28 cornea donors that year with a family consent rate of 5%. By the end of the project in 2012 the program was in effect in twenty-three hospitals and had registered a total of 4,473 alerts with 22 organs and 75 corneal donors and a family consent rate of 25%.

With this background context on the historical development of organ donation and transplantation in Lebanon, the next three sections will detail the characteristics of the Lebanese organ donation system using a governance lens. As presented earlier, the Lebanese system will be described using the three levels of the Mikkelsen-Lopez et al. (2011) governance framework, namely service delivery, governance and regulation and society and culture.

### 4.2. SERVICE DELIVERY AND SOCIETY AND CULTURE

Similar to most systems worldwide, the system of organ donation and transplantation in Lebanon consists of two separate processes for organ donation: living organ donation and deceased organ procurement both of which culminate in the transplantation process. All three processes are regulated by NOD-Lb as stipulated by a series of laws and decrees that govern the system.

#### 4.2.1. Living Donation

Both living related (LRD) and unrelated (LURD) organ donation are possible in Lebanon although the latter requires more regulation and precaution to avoid preying on the vulnerable and promoting organ trafficking (Delmonico et al., 2011; Furlow, 2012). As specified in ministerial decree 1/1765 in 2014, both LRD and LURD are subject to strict rules and regulations. They follow a rigorous process (figure 4.1) which includes undergoing medical and psychological evaluations, obtaining ethical approval from a committee designated by the MoPH and submitting a completed file to NOD-Lb for

control and review. The final decision is taken by the MoPH once the process is complete. Only then can the transplantation process be initiated.

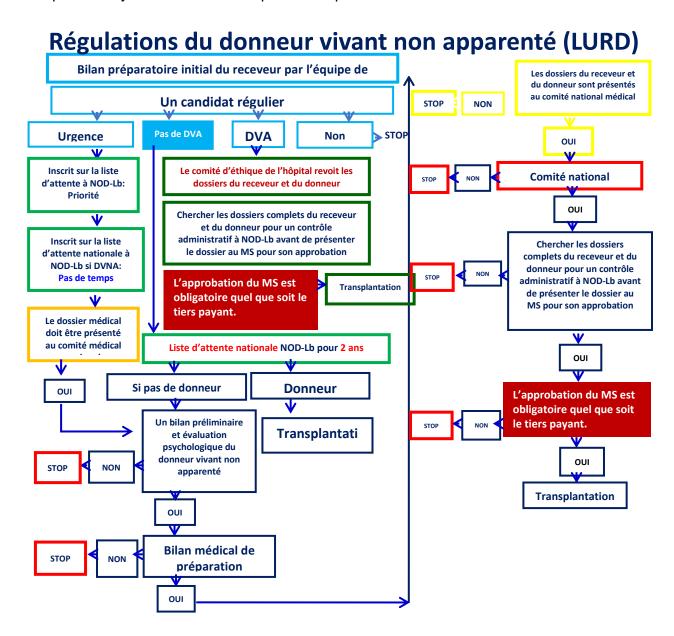


Figure 4.1: Summary of living donation process

Source: NOD-Lb, 2017

Both the donor and the recipient need to sign informed consent forms. In Lebanon, LRD comprise individuals who are genetically related up to the 4th degree and include

parents, siblings, grand-parents, uncles, aunts, cousins, nephews, nieces as well as spouses and adopted children. In addition, the donor should be at least 21 years of age for LRD and not less than 25 years for LURD. For the latter, the recipient has to have been registered on the national waiting list for at least 6 months.

#### 4.2.2. Deceased Procurement

The Lebanese deceased organ procurement process, described in figure 4.2, was developed along the lines of the Spanish model which is recognized as the most efficient example of organ donation, since Spain is the only country to have achieved steady improvements in cadaveric organ donation over 15 years (Matesanz et al., 2017). In more recent years, Lebanon has signed an agreement with the *Agence de la Biomédecine*, which regulates the French organ donation system, and as such has been using their guidelines.

The process (figure 4.3) is based on early donor detection and referral, rigorous follow-up, timely brain death diagnosis, familial consent and aggressive management. In accordance with the Spanish model, the Lebanese process incorporates a rigorous organizational structure with coordinators at all levels (national, regional and local) and quality assurance programs as essential components of any successful process. The national coordinator (NC) is at the center of the system and is assisted by regional and local coordinators.

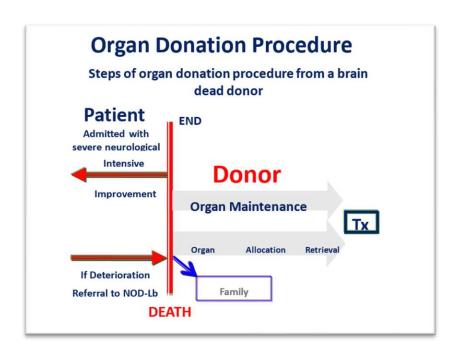


Figure 4.2: Deceased organ procurement process

Source: NOD-Lb 2017

Another cornerstone of the Lebanese process, inspired by the Spanish model, is its focus on the family approach. Lebanon has always followed an opt-in system whereby a donor indicates his will to donate his organs postmortem by signing a donor card while alive. A national donor registry managed and updated by NOD-Lb has been in place since the end of 2009. In Lebanon, these cards are not legally binding and according to the law of 1983, organ removal can only be carried out with the consent of the family. This makes family approval an important and necessary condition in the Lebanese context, and therefore, obtaining it, has been one of the primary concerns of the procurement process.

The family of the potential donor is approached through a series of interviews conducted by both the ICU physician who announces the "death" to the family, and the hospital coordinator who requests and secures their agreement for organ donation. The latter has been trained in the methods and timing of family approach and the strategies used to identify their fears and overcome their objections. During these interviews the coordinator explains the concept of brain death to the family, addresses their concerns and alleviates their doubts. At least three interviews per family are necessary before considering the family refusal as final. In case of consent, the hospital coordinator makes the necessary arrangements with the internal security forces and the army and the Lebanese red Cross to ensure a timely and rapid delivery of the donated organs.

	• Cardiac arrest: responsibility of the ER physician and/or nurse and the hospital coordinator OPC.
Detection and	<ul> <li>Brain death: Every patient with severe cerebral injury, intubated and GCS &lt; 5</li> <li>Responsibility of the ICU physician, ICU nurse and OPC</li> </ul>
referral	The sponsibility of the ICO physician, ICO huise and OFC
Brain death	•Responsibility of the ICU physician, neurologist and/or neurosurgeon
diagnosis	
	•Responsibility of the ICU physician, ICU nurse and OPC
Donor maintenance	
	•Responsibility of the ICU physician to announce the death
Family approach	Responsibility of OPC and/or NOD-Lb coordinator to request donation
арргоасп	
	NOD In NC 9 modical director access the suitability of natural denors and the equitable distribution of excess
	<ul> <li>NOD-Lb NC &amp; medical director assess the suitability of potential donors and the equitable distribution of organs</li> <li>Regional coordinators ensure the traceability of the organs</li> </ul>
Organ	• Transplantation centers establish rules and protocols
allocation	Immunology labs provide test results
	OPC: makes the arrangements with the operating room, ensures 2circulating nurses and one scrub nurse, and coordinates with NOD-Lb
Organ	• NOD-Lb coordinator: ensures that surgeons and physicians are set for retrieval with all the necessary material, calls the
retrieval	recipients, collects all tests results needed
	Responsibility of the transplant surgeons and their hospitals
Organ	NOD-Lb will make the necessary arrangements with the internal security forces and the
transplantatio	army to ensure a timely and rapid delivery of the donated organs
n	
	•NOD-Lb coordinator has to call the transplant centers and get information about the result
	of the transplantation and calls the donor's family and the staff of the donating hospital to
Feedback on transplantatio	thank them.
n	

Figure 4.3: Breakdown of the deceased organ donation process

Source: adapted by the author based on information from NOD-Lb

# 4.2.3. Transplantation Activity

Organ transplantation is the culmination of any organ donation process and yet it is a process in and of itself. The treating physician (cardiologist, nephrologist, pulmonologist, hepatologist, ophthalmologist) determines when a transplantation is necessary and refers the patient to a transplant center for evaluation. Upon successful completion of the evaluation process, the transplant surgeon in coordination with the treating physician sends the patient, to NOD-Lb, to register on the national waiting list. The same patient cannot be registered in more than one transplant center.

Matching of recipients and donor is based on age, blood group, body size, urgency, tissue typing, time on the waiting list and the immunization status of the patient. Other issues such a social status, religion, wealth, political affiliation, ... are never taken into consideration. A series of rigorous tests ensures that the donor and recipient are well-matched before the transplant surgeon and the treating physician sign off on the transplantation. In addition, no transplantation can occur in the absence of ethical approval.

#### 4.2.4. Society and culture

Lebanon has always followed an opting-in system whereby organ retrieval is only possible when a person has explicitly indicated consent to post mortem donation by signing a donor card. This can be done in person by visiting the NOD-Lb offices or online through the NOD-Lb platform. However, in practice organ removal is only

practiced upon approval of the family regardless of whether the deceased has signed a donor card or not.

# 4.3. GOVERNANCE AND REGULATION: PPP BETWEEN NOD-LB AND MOPH

ALDOR or the Lebanese Association for Organ and Kidney Donation and Transplantation was established in 1992 as an official NGO with the aim of spreading awareness about donation after death. The development of the NGO was the result of private, individual efforts, stemming from the collaboration of the concerned health professionals from university hospitals and the only transplant center available. Given that the kidney was the only organ transplanted in Lebanon at that time, the NGO was initially set up with kidney donation in mind. With time as more centers were established, the founding members decided that the NGO would encompass all organs to economize time and avoid duplication of efforts.

Officially ALDOR was mainly concerned with awareness and promotional activities related to organ donation. However, some of the transplant professionals on the NGO board worked in center 1 and were involved with organ procurement as part of the exercise of their medical profession. This blurred the lines between the NGO and center 1 in the eyes of transplant professionals from other centers and although the latter were included as members on the NGO board, the NGO was always perceived as linked to center 1 and, given its board, was attributed functions that went beyond its official role.

Whereas the intention was to have transplant centers collaborate with each other in terms of the distribution of organs, the circumstances of the inception of ALDOR hampered the process making it difficult to get transplant surgeons to cooperate with the NGO. There was always the fear of favoritism and lack of impartiality when it came to the fair distribution of organs. Each center wanted to promote transplantation and ensure organ procurement and it became difficult for ALDOR to operate on a national level due to competing interests and concerns about preferential treatment. There was no standardized system; each center had its own structure and work ethic, issued its own donation cards and pursued its own agenda. This created confusion and ethical concerns as the focus shifted from altruistic donation in an organized and controlled manner to a race towards transplantation by all means.

#### 4.3.1. The creation of NOD-Lb

In 1999 the MoPH and the Lebanese Order of Physicians (LOP) took the joint decision to concentrate all organ donation efforts in a single, unified, national organization and initiated the process through a decree (No 509/1999) with four articles intended to promote organ donation planning and lead to the development of a Lebanese system of organ and tissue donation and transplantation. The decree mandated the creation of a committee of thirteen members consisting of the MoH as president of the committee, both the Beirut and Tripoli presidents of the LOP, the head of the Medical and Scientific Ethics Committee, the deans of the Lebanese University, American University of Beirut and Saint Joseph University of Beirut medical schools, the head of the Lebanese Red Cross, the heads of the committees for organ transplantation and organ donation at the

LOP Beirut and three representatives from civil society that were chosen by name. The tasks of this committee were to draft the Lebanese organ donation and transplantation system, set up an information database and communication network, establish the standards and regulations for organ donation to be adopted by all, prepare templates for questionnaires and documents relative to the doctors, recipients and donors and propose mechanisms of collaboration and best practices to implement the process and apply the legislative decree. The committee was to be housed in the offices of the LOP in Beirut and appointed a treasurer chosen by the MoH in agreement with the President of the Beirut LOP.

It appears that this committee was set up in form only by the MoH and President of LOP at the time to potentially pave the way to establishing a system for organ donation in Lebanon. Roles were not clearly attributed and in fact, the committee members did not necessarily have the expertise to address the issue of organ donation let alone frame a project, prepare guidelines or establish specifications and standards for the process. As a result, there is no evidence that the committee ever met and there are no traces of any action initiated or decision taken by it. In fact, there was little official activity in the following decade where most of the work on the organ donation front consisted in raising awareness and organizing courses and conferences in collaboration with ALDOR. Organ procurement was the realm of transplantation centers who had conflicting, often self-promoting goals and were duplicating their efforts. There was no clear overseer and no modalities to safeguard against unethical practices.

There was a clear need for an organization to take charge. In 2004, the name of the committee was amended to include tissue donation as the eye bank became part of the national vision for organ donation (ministerial decree 4401). There was an official attempt in 2005 (ministerial decree 61) to establish the National Organization for Organ and Tissue Donation and Transplantation (NOD-Lb), specifying its tasks and organizing its work but this did not materialize until 2009 with a new ministerial decree (ministerial decree 65) that established NOD-Lb and concretely highlighted the mechanisms for its governance and organization.

This new decree consisted of thirteen articles that clearly delineated the creation and organization of NOD-Lb and several specialized supporting sub-committees including a committee of physicians from each of the transplant centers, a committee of coordinators from each of the participating hospitals and a committee of medico-legal physicians. Unlike the previous decree that specified committee members according to their official positions, this one clearly specified the president, vice president and three members by name without referring to their titles or positions. Even the president of the organization who was also the MoH at the time was referred to by name rather than position. The same five individuals made up the board of administration of the organization. This board had several tasks including supervising the application of the organ donation and transplantation laws and regulations in all hospitals as well as coordinating with them for the notification and follow-up of cases of brain death and the allocation of organs in a fair and consistent manner. In addition, it was responsible for

establishing guidelines, maintaining a national waiting list, evaluating the transplantation centers and reporting findings to the MoPH.

Sanctioned by law and allocated a budget from the MoPH (ministerial decree 979) the organization was now able to function effectively. Moreover, in 2009, the Spanish government, through the Spanish Agency for International Development Corporation granted NOD-Lb financial and technical help through the DTI. In addition, several pharmaceutical companies contributed additional funds providing NOD-Lb with the financial capacity to finally start implementing a Lebanese system adapted from the Spanish model.

In 2012, article 30 of the Lebanese code of medical ethics was amended to designate NOD-Lb as the only official body responsible for supervising and coordinating all organ, tissue and cell donation and transplantation activities in Lebanon. In 2014, this was further formalized by ministerial decree 722 which stated in four articles that with respect to organ donation and transplantation, all activities should be approved by NOD-LB, all conferences should be under its patronage and all collaborations should follow a predetermined protocol signed by both parties and ratified by the MoPH. Table 4.1 below summarizes the important milestones in the history of organ donation in Lebanon.

Table 4.1: Timeline for organ donation in Lebanon

Year	Event
1972	2 kidney transplants from LRD
1983	Law 109: organize organ donation
1984	<b>Practical application decree 1442</b> : requirements of transplant centers and brain death diagnosis
1985	1 <sup>st</sup> kidney transplant center
1990	1 <sup>st</sup> kidney transplant from DBD
1999	Ministerial decree 509: creation of a national committee for the development of organ and tissue donation and transplantation in Lebanon
2000	Establishing the National Eye Bank Quarantina
2004	Ministerial decree 4401: amend the naming of the committee for establishing a national system for organ and tissue donation and
	transplantation (incorporate eye bank within the system)
2005	Ministerial decree 98: establish the national system for organ and tissue donation and transplantation
2008	Ministerial decree 979: declare coverage of organ and tissue donation procedure by the MoH
2009	Ministerial Decree 65 defines the executive board of NOD-Lb and
	describes the Lebanese system of organ and tissue donation and
	transplantation.
2012	Lebanese Code of Medical Ethics (Code 240, art 30): gives NOD-Lb the
	exclusive responsibility of organs, tissues and cells procurement and
	transplantation in Lebanon.
2014	Ministerial decree 722: legal terms of reference for NOD-Lb

Source: Adapted from NOD-Lb

#### 4.3.2. The role of NOD-Lb

The official mission of NOD-Lb as detailed in the ministerial decree (1/65) is to "supervise and coordinate all organ donation and tissue procurement and allocation in Lebanon" while guaranteeing that "safety, medical ethics and equity are respected" throughout the process.

"... its mission consists of increasing the organ and tissue donation rate to reach self-sufficiency through implementing a Lebanese model for organ and tissue donation and transplantation"

#### - NOD-Lb website -

Being the authority of reference, NOD-Lb makes informed decisions and suggests legislature that it then submits to the MoPH for approval and legalization. It is responsible for elaborating protocols to guide all donations and transplantation procedures. At the administrative level it has taken on the role of overseer supervising the implementation of the Lebanese donation and transplantation system for organs, tissues and human cells in Lebanese hospitals and solving problems as they arise. It is responsible for coordinating between transplant centers and hospitals in the follow-up of patients diagnosed with brain death to ensure the procurement and fair distribution of organs according to preset procedures. In addition, it conducts routine hospital inspections, maintains patient files, follows up on daily transplant activities and basically steps in whenever and wherever needed. NOD-Lb also established the rules of inclusion in the national waiting list and the national registry of donation and transplantation and is in charge of updating the registry of potential donors and issuing donation cards. It is responsible for developing the continuous education of health professionals, ensuring approval for the process from religious entities and promoting organ and tissue donation to the general public through public campaigns and the use of different media platforms. Finally, NOD-Lb is an active participant in all organ donation activities and societies both in Lebanon and abroad. This includes organizing

medical conferences, planning and conducting research and contracting with parties and organizations to promote the organ donation process at the local, regional and international levels.

NOD-Lb established and supervises the National Organ Procurement Network in Lebanon as a unified system with a central office affiliated to twenty-three hospitals functioning under the umbrella of the MoPH. At its peak, this network included 140 health professionals, 96 of whom are registered nurses from Intensive Care and Emergency Units and 46 are physicians specialized in critical care, anesthesiology, neurology and coroners. In this system, coordination is achieved at three levels: national, regional and local. NOD-Lb coordinates with a committee of regional coordinators composed of twelve physician coordinators including a head coordinator, a critical care physician for each region (Metn, Keserwan, Byblos, Bekaa, Chouf, North and South Lebanon regions) three regional coordinators for Beirut and a national pediatric coordinator. NOD-Lb employs three full-time (NC, administrative secretary and assistant local coordinator) and seven part-time (medical director, lawyer, public relations and fundraising consultant, local coordinator, accountant, social media consultant and IT consultant) professionals.

#### 4.3.3. The status of NOD-Lb

The status of NOD-Lb remains somewhat ambiguous as it is neither an NGO nor a governmental agency but rather an autonomous private entity created by a decree and financed through a governmental budget which, together with the decree, provides it

with a legitimacy to operate. The confusion is made clear by the different ways in which various actors describe the status of the organization.

"NOD-Lb does not have a clear status. It is neither an NGO nor an independent public agency. Practically however, it has the authority conferred unto it by the MoPH and a legitimacy since it is financed by public funds. NOD-Lb is recognized officially and is able to operate "defacto" with a known status under a clear strategy."

- MoPH participant -

"NOD-Lb is a governmental organization working under the umbrella of the MoH."

- NOD-Lb website -

"NOD-Lb is considered an autonomous agency that is privately run but partially publicly funded through a budget allocated by the MoPH."

- NOD-Lb participant -

"NOD-Lb is affiliated to the MoPH"

- NOD-Lb participant -

The private aspect was seen as advantageous as it also offered a layer of protection against religious affiliation, political sway and general corruption. As a private entity, it was meant to be shielded from political interventions and aspirations. This would provide the organization a higher level of administrative independence.

It is noteworthy that although the organization is affiliated to the MoPH through the decree and its dependence on public funds, it lacks visibility within the MoPH. It is not included in the National Health Plan for Lebanon and does not appear under any of the programs, committees, statistics or laws published on the MoPH website. In fact, the only mention relates to the decrees governing the importing and exporting of tissues and a mention of a national awareness campaign in 2016 (MoPH website).

### 4.3.4. The governance of NOD-Lb

Although the structure of NOD-Lb was defined by law (ministerial decree 1/65) in 2009, the latter remains vague as to the specific duties of each individual. The bulk of the work fell by choice and expertise to the vice president (also considered the medical director) and the NC (included as a board member). In addition, since the president named in the ministerial decree was also the MoH at the time, this nomination remained ambiguous and the position was subsequently attributed to the current MoH with no clear consensus on what the role of the individual actually named by Ministerial decree as president became once he was no longer MoH. The role of the Director General (DG) of the MoH although prominent given that he is the constant in the MoPH as different MoH come and go is also not defined by law. He is not mentioned in the ministerial decree but is clearly mentioned in the governance of NOD-Lb as part of the governing body.

"The National Organization for Organ and Tissue Donation and Transplantation is a nonprofit organization governed by a Board designated by a ministerial decree (2009,65/1) and the general director of the MoH."

#### - NOD-Lb website -

The relations between NOD-Lb officials and the government is limited to their interactions within the MoPH. Their main points of contact and negotiation are the MoH and the DG of the MoPH. Six MoH with different term durations, political affiliations, professions and specializations were honorary presidents of NOD-Lb since its inception. It is worthy to note that the DG of the MoPH remained the same during that time.

The structure set forth in Ministerial decree 1/65 remains mostly unchanged since NOD-Lb's inception The organigram of NOD-Lb developed as per the law is presented in figure 4.4. At the head of the organization are the current MoH and the DG of the MoPH. The president of NOD-Lb remains the MoH that was designated by name rather than title at the inception of the organization. In fact, he has long disappeared from the scene and is now replaced by the current MoH. The organigram clearly shows the presence of a president embodied in the figure of the MoH (named in person not by title) and a vice president who is also the medical director (a nephrologist).

The understanding is that the MoPH is officially in charge of organ donation, procurement and transplantation in Lebanon. However, since it is more of an administrative body that lacks the medical expertise for decision making in the context

of organ donation, that task was delegated to NOD-Lb. In practice, NOD-Lb is the reference and decision-maker although all decisions have to be countersigned and approved by the MoH. Decisions are made by the vice president/medical director and NC after consultation with the transplant centers and/or regional coordinators and informing the board. In fact, the board is mostly concerned with administrative decisions and does not actively participate in medical-related ones. Recommendations are then presented to the general director of the MoPH and if approved they are countersigned by the MoH to become officially effective.

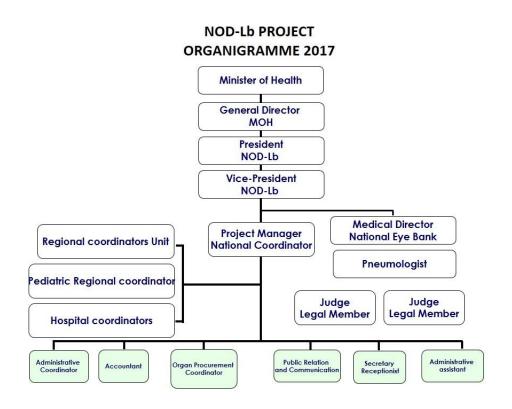


Figure 4.4: NOD-Lb organigram

Source: NOD-Lb 2020

Since 2005 all decrees related to organ donation have been suggested by NOD-Lb. The medical director of NOD-Lb identifies problems and proposes solutions based on consultations with the national and regional coordinators as well as information from health professionals involved in the transplantation process and the medical committee. The proposed solutions are then presented to the NOD-Lb board for approval before suggesting them to the DG. The DG in turn discusses and reviews the suggestions and if he approves, which is usually the case, he will recommend them to the MoH for his final approval and countersignature. At that point, the ministerial decree becomes officially effective.

Financially, NOD-Lb heavily depends on the budget allocated by the MoPH. It is clearly specified in article 10 of ministerial decree 1/65 that the MoPH is to allocate a specific lump sum from its yearly budget to NOD-Lb. The amount was to be disbursed via the executive board of the Rafik Hariri University Hospital and was to be revised based on need and medical advancements.

Practically, the amount allocated depends on the political and financial situation of the country at the time as well as the extent of the current MoH's support to the program. In general, the budget allocated from the MoPH is usually inadequate and does not ensure the running costs of the organization let alone allow for any promotional activities. The organization's expenses including monthly salaries of employees and administrative overheads such as rent, utility bills as well as partial coverage of the donation procedure and the incentives for all the health professionals involved in the process have to be met

regardless of the budgetary constraints of the government. Moreover, the budget is never delivered in a timely manner. To retrieve the funds, which are disbursed by the Governmental Audit Court, the organization needs to justify their expenditure and present detailed bills for all expenditures. Although not necessarily intended, the budget is actually used as a post ante control mechanism whereby NOD-Lb is asked to justify expenses in order to retrieve money retrospectively long after it has been spent. As a result, alternative methods of financing including self-financing, fundraising and crowdfunding as well as actively seeking donations from various funding agencies, pharmaceutical companies and embassies were employed.

# 4.3.5. NOD-Lb as a third sector organization

Although organ donation is a national public health concern that should be addressed by the public sector, there was no unit in the MoPH capable of carrying out the task at the time. Moreover, Lebanon was emerging from a civil war with a weakened public health system and no means of creating a public agency responsible for organ donation like those available in major European countries. The public sector lacked the necessary expertise and addressed this issue through collaborative governance mechanisms that were previously tested and had shown successful results in other health related endeavors.

Therefore, the alternative was to rely on a committee consisting of a select group of professionals who had the necessary expertise, were committed to organ donation and interested in investing the time and effort needed to move it forward. With time, the

necessary decrees were passed and the committee evolved to become an organization, sanctioned by the MoPH, with a board, budget and official terms of reference so that it could function efficiently.

"... it was difficult at the time to create a public agency responsible for organ donation so the choice was to establish a committee made up of individuals like the Medical Director and National Coordinator of NOD-Lb who were personally committed to the issue. With time, the committee became an organization with a framework and budget so that it could function."

- MoPH participant -

The creation of NOD-Lb as a third sector organization to handle the organ donation and transplantation needs in Lebanon was a necessity to ensure self-sufficiency by organizing the Lebanese system of organ donation. This consisted of structuring and regulating the living organ donation process as well as devising, implementing and supervising the deceased organ donation process.

#### 4.3.6. The authority of NOD-Lb

In practice, it is NOD-Lb who provides the actual expertise, makes the decisions, suggests the laws, rules and regulations, implements them on the ground and supervises all organ and tissue donation and transplantation in Lebanon. The contribution of NOD-Lb is essentially behind the scenes as it does not appear in the official decree. NOD-Lb suggests, but the MoPH remains the official reference. It has

the legal power and authority to make and enforce all laws concerning organ donation and transplantation in Lebanon. In principle, the MoPH has authority over the public hospitals. Yet, the MoPH employees including the MoH who are not specialized physicians and lack the expertise in this field are vulnerable to emotional blackmail and prefer to refer difficult cases pertaining to living donation to NOD-Lb insisting that approval is dependent on the organization. Phrases such as "get NOD-Lb to approve" and "If NOD-Lb accepts we agree to the transplantation" are common answers among MoPH employees in these instances. Moreover, although NOD-Lb enjoys the administrative independence to run the organization as it sees fit, it relies heavily on public funds.

The process is set up in a way that the government controls the money and power but NOD-Lb is in charge of the planning, decision-making and implementation. In terms of accountability, NOD-Lb is held accountable for the procurement while the hospitals are held accountable for the transplantation. However, to date there is no formal means of assessing or promoting accountability.

### 4.3.7. Financing Organ Donation in Lebanon

Once the donor is approved by NOD-Lb, all the deceased donation expenses from the time of brain death diagnosis to the end of the hospital stay are completely covered by the MoH (Ministerial Decree 1/979, 2008). The payment is based on a flat fee, determined by NOD-Lb, that is not included in the financial ceiling of the hospital. NOD-Lb covers physician and healthcare personnel fees up to a maximum of US\$ 2000. The

transplantation is covered by the third-party payer of the recipients. The MoH pays for all immuno suppressive drugs for life.

# 4.4. PERFORMANCE OF THE LEBANESE SYSTEM OF ORGAN DONATION: RATES, ACTIVITIES AND PMSS FRAMEWORK

This section presents data compiled by NOD-Lb to help assess their performance and the progress made in terms of increasing donation and conversion rates as well as raising public awareness through the increase in familial consent and the number of donation cards. In addition, a qualitative evaluation of the specificities of the system in terms of organ donation and transplantation activities will be presented based on the Action Plan on Organ Donation and Transplantation outlined by the European Council. Finally, the description of the performance of the system will conclude with the implementation of PMSs framework presented in chapter 1.

## 4.4.1. Quantitative rates for organ donation and transplantation

As seen in Figure 4.5, a total of 2,166 organs, 97% kidneys (2091/2166), have been transplanted from both living and deceased donors in Lebanon between 1985 and 2018. The rates of transplantation have remained fairly stable varying between a minimum of 14 pmp in 2015 and a maximum of 26 pmp in 2013 (table 4.2). The majority of these transplant activities consist of kidney transplantations from living donors. The highest rate of actual deceased donation was 5 pmp in 2014 while the highest rate of living donors is 22.7 pmp in 2013.

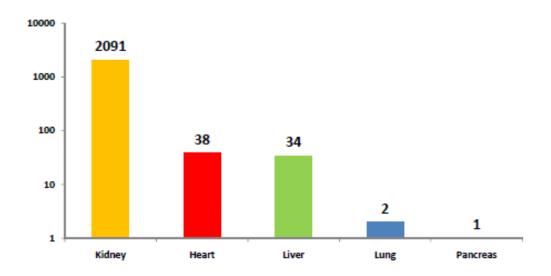


Figure 4.5: Total Number of Organs transplanted in Lebanon from living and deceased donors 1985-2018

Source: NOD-Lb, 2018

Table 4.2 clearly shows that the organ donation process was on a steady increasing path between 2010 and 2014 but has been stagnating ever since. It is important to note that 2013 indicated the end of the SEUSA program which also saw the end of the funding allocated by the Spanish government. Table 4.3 shows the evolution of the deceased donor process in Lebanon.

Table 4.2: Key statistics describing the Lebanese Organ Donation System 2010 - 2018

Indicators	Year								
	n(pmp <sup>1</sup> )								
	2010	2011	2012	2013	2014	2015	2016	2017	2018
Population <sup>2</sup>	4.3	4.3	4.3	4.8	5.0	5.0	5.0	5.0	5.0
LD <sup>3</sup>	70(16.3)	86(20.0)	108(25.1)	98(20.4)	81(16.2)	71(14.2)	80(16.0)	109(21.8)	116(23.2)
Actual DD <sup>4</sup>	2(0.5)	11(2.6)	10(2.2)	7(1.6)	9(2.1)	5(0.85)	6(1.4)	13(3.0)	4(0.9)
DBD <sup>5</sup>	2(0.5)	11(2.6)	10(2.2)	7(1.6)	9(2.1)	5(0.85)	6(1.4)	13(3.0)	4(0.9)
DCD <sup>6</sup>	27(6.3)	19(4.4)	28(6.5)	15(3.1)	8(1.6)	10(2.0)	2(0.4)	2(0.4)	3(0.6)
Transplants Deceased tra	82(19.6) nsplants	109(22.7)	123(24.6)	115(23.0)	94(18.8)	81(16.2)	84(16.8)	125(20.5)	123(24.6)
Kidney Liver	4(0.9) 1(0.2)	15(3.5) 2(0.5)	12(2.8)	10(2.1) 4(0.8)	10(2.0) 1(0.2)	6(1.0) 2(0.3)	5(1.0)	10(1.2) 1(0.2)	4(0.8) 1(0.2)
Heart Lung		6(1.4)	3(0.7)	2(0.4)	2(0.4)	2(0.3)		6(1.0)	2(0.4) 1(0.2)
Corneas	62(14.4)	50(11.6)	67(15.6)	42(8.8)	32(6.4)	28(5.6)	10(2.0)	20(4.0)	8(1.6)
Living transpla	ants								
Kidney Liver	76(17.7) 1(0.2)	85(19.8) 1(0.2)	108(25.11)	109(22.7)	81(16.2)	70(11.9) 3(0.5)	80(16.0)	106(21.2) 3(0.5)	107(21.4) 9(1.8)

Source: NOD-Lb

Table 4.3: Critical pathway for deceased organ donors, Lebanon 2010-2019

Indicator	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Population	4.3	4.3	4.3	4.3	5.0	5.0	5.0	5.0	5.0	5.0
Potential Donor <sup>7</sup>	95	66	72	49	41	43	28	53	53	55
Eligible Donor <sup>8</sup>	57	49	56	45	32	32	18	41	28	36
Families approached	41	38	42	20	24	20	13	30	19	16
Families consented	4	11	10	7	9	5	6	13	4	6
Actual Donor9	2	10	10	7	9	5	6	13	4	6
Utilized Donor <sup>10</sup>	2	8	6	7	5	3	3	8	2	2
Conversion Rate <sup>11</sup>	0.5	2.6	2.3	1.6	2.1	1.2	1.4	3.0	0.9	1.4

Source: NOD-Lb

<sup>&</sup>lt;sup>1</sup> pmp = Rate per million population

<sup>&</sup>lt;sup>2</sup> Population by 10<sup>6</sup>

<sup>&</sup>lt;sup>3</sup> LD = Living Donors

<sup>&</sup>lt;sup>4</sup> DD = deceased donor

<sup>&</sup>lt;sup>5</sup> DBD = deceased donor after brain death

<sup>&</sup>lt;sup>6</sup> DCD = deceased donor after circulatory death

<sup>&</sup>lt;sup>7</sup> Potential donor: A person whose clinical condition is suspected to fulfil brain or circulatory death criteria

<sup>&</sup>lt;sup>8</sup> Eligible donor: A medically suitable person who has been declared brain dead

<sup>&</sup>lt;sup>9</sup> Actual donor: A deceased person from whom at least one organ has been recovered for the purpose of transplantation

<sup>&</sup>lt;sup>10</sup> Utilized donor: An actual donor from whom at least one organ was transplanted

<sup>&</sup>lt;sup>11</sup> Conversion rate: The number of actual donors divided by the number of potential donors

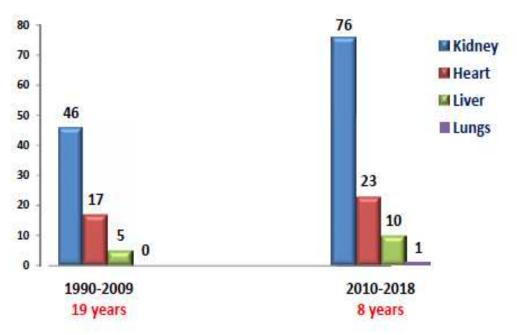


Figure 4.6: Deceased donation before/after the implementation of the deceased procurement process

Source: NOD-Lb, 2018

Although there is room for further improvement, the conversion rate indicates better detection and management of donors and therefore a more efficient use of the system. Moreover, although using organs from deceased donors has increased in Lebanon after the implementation of the deceased procurement process (figure 4.6), transplantation in Lebanon remains heavily dependent on living donors (figure 4.7). It is interesting to note however, that in recent years the living donors in Lebanon have been predominantly living related donors whereas before 2014, more than half the donors were living unrelated. This shows success in countering organ trafficking. However, deceased donors were not able to bridge the gap.



Figure 4.7: Total number of organs transplanted in Lebanon from living and deceased donors 2010-2018

Source: NOD-Lb, 2018

Furthermore, as seen in figures 4.8 and 4.9, the proportion of real donors, families approached, and donation cards increased between 2010 and 2018 point towards a greater awareness and acceptance of deceased organ donation. Yet, similar to what has been observed in other studies, although the climate was favorable for organ donation the statistics tell a different story (Soyama and Egushi, 2014). Today, ten years later, although the refusal rates have been considerably reduced, deceased donation rates remain pointedly low (Stephan, 2016).

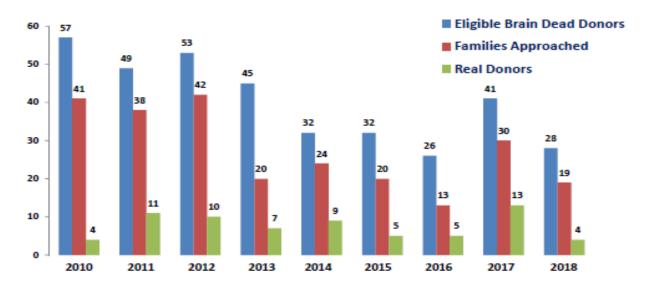


Figure 4.8: Results of family approach 2010-2018

Source: NOD-Lb, 2018

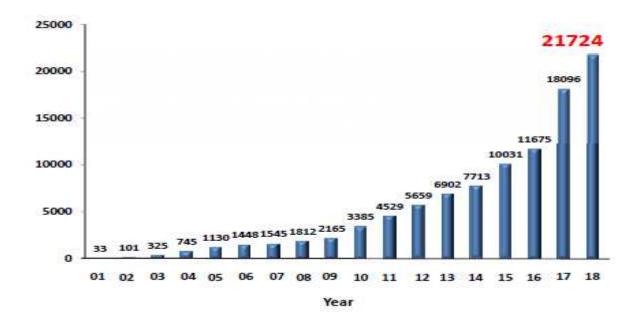


Figure 4.9: Cumulative Number of donation cards 2001-2018

Source: NOD-Lb, 2018

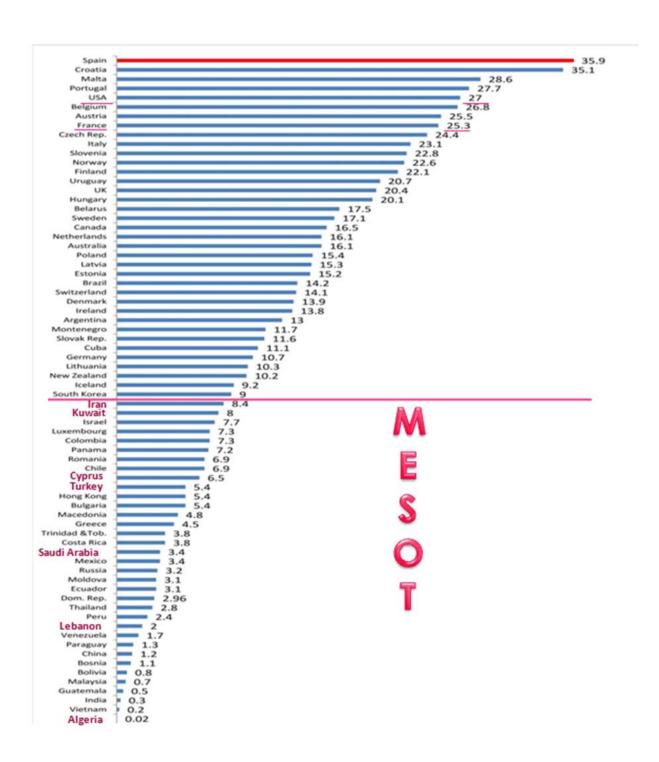


Figure 4.10: Worldwide deceased organ donation rates. December 2015

Source: International Registry in Organ Donation and Transplantation, 2015

Figure 4.10 shows worldwide deceased donation rates in 2014 which marked the end of the SEUSA program in Lebanon. It is clear from the figure that there were differences among countries in terms of deceased donation rates achieved. Eighteen countries joined the SEUSA program around the same time as Lebanon. Examples include Algeria, Bulgaria, Croatia, Cyprus, Czech Republic, Greece, Malta, Portugal and Turkey (Manyalich, 2013). However, by the end of the SEUSA program, some of these countries, such as Croatia and Portugal, had moved on to rival the best in terms of deceased donation rates. In comparison, with the exception of Algeria, Lebanon remained at the bottom of the charts.

# 4.4.2. Qualitative assessment of organ donation and transplantation activities Table 4.4 presents a more qualitative assessment by summarizing the process of organ donation and transplantation in Lebanon using the EU action plan (Bouwman et al, 2009-2015). It emphasizes the steps that have been taken to ensure that the process is up to the standards practiced in other countries. According to this list the main shortcomings of the present system appear to be the lack of collaboration on a regional level and the necessity to evaluate post-transplant results on a national level.

Table 4.4: Implementation of the Action Plan on Organ Donation and Transplantation outlined by the European Council

Challenge 1: Increas	ing organ availability
Priority action	Implementation in Lebanon
1: Promote the role of transplant donor coordinators	Since 2010, there have been 23 hospital coordinators (2-4 per hospital), 5 regional coordinators (1 per mohafaza), a part-time assistant central coordinator and a national coordinator. All the regional coordinators are intensivists while the hospital coordinators are nurses. All coordinators have received training before being appointed.
2: Promote Quality Improvement Programs 3: Exchange of best	Since 2010, it includes: double checking the information on the files, auditing the hospitals, testing and documenting, specifying tasks and procedures, preparing brochures.  NA
practices on living donation programs among MESOT	
	ing the efficiency and accessibility of transplant systems
4: Improve the knowledge and communication skills of health professionals and patient support groups	Since 2010, it includes: training courses for coordinators on reanimation, allocation rules and communication skills both locally (970 nurses and 250 physicians from all parts of Lebanon engage in 2.5 days of theory and 0.5 day of practical exercises in a simulation lab) and abroad (about 10 nurses, 12 physicians sent to France, Spain and Italy), setting-up a hospital audit system
5: Facilitate the identification of organ donors across Lebanon	Since 2010, the national coordination network made up of a hospital organ procurement committee consisting of an intensivist, a neurologist, a medico legal physician and 2 coordinators one from ER and one from CCU supervised the work of the local hospital coordinators and investigated any problem that they faced while trying to procure as many organs as possible
6: Enhancing the organizational models of organ donation and transplantation	Organ procurement is still either rudimentary or non-existing in the immediate surrounding countries. We have proposed to help Iraq and Jordan, but the security situation is a big obstacle for the time being. It is not the right time to talk about Syria.
7: Promote EU-wide agreements on aspects of transplantation medicine	We apply the European regulations specifically Spanish and French No agreements in MESOT; financial concerns
8: Facilitate the interchange of organs between national authorities	We do not have yet a specific law to allow us to share organs with KSA and Kuwait. No official documents or issues of commercialism.
	ing quality and safety
9: Evaluation of post- transplant results	The project is in process. The auditing, system that is to be put in place soon, will ensure post-transplant evaluation
10: Promote a common accreditation system	This will be done very soon with the MoH hospital accreditation criteria

Source: Compiled by Author based on Action plan on Organ Donation and Transplantation (2009-2015): Strengthened Cooperation between Member States

## 4.4.3. The PMSs framework and the Lebanese system of organ donation and transplantation

Table 4.5 describes the PMSs for the Lebanese system of organ donation and transplantation. Similar to the models described previously, this system has a clearly stated mission and vision, a structured organigram and specified key success factors and performance indicators. However, whereas the other countries all have strategic plans, performance evaluation strategies and appear to make use of PMSs results to further improve the system, these elements seem to be missing from the Lebanese system. One possible explanation put forth by NOD-Lb is the lack of a confirmed budget which makes it difficult to set targets and strategic plans. This was done at the beginning of the program when NOD-Lb was still benefiting from the Spanish support but could not be continued later.

"It is difficult to put strategy and targets when we receive the budget of 2018 in 2020"

- NOD-Lb participant -

Another possible explanation could be the ambiguity of the status of NOD-Lb which is neither a public nor a private entity and therefore would not have a clear vision on who's responsibility it would be to devise such a plan. As seen in the previous models, when the regulator was the public sector it was the responsibility of the Ministry of Health. However, when the regulator was in the private sector it became the responsibility of the regulator. In this case, the management of NOD-Lb considers the organization a public entity whereas the government views it as a private entity.

As explained earlier, NOD-Lb uses indicators such as donation and conversion rates, number of donation cards and family consent levels as indicators of performance and progress. The lack of more formal performance evaluation measures will be revisited in the second section of part III.

Table 4.5: The Lebanese model of organ donation and transplantation through the lens of the PMSs framework

PMSs components	Lebanese Model
Vision & Mission	<ul> <li>Save and enhance the lives of as many people as possible in Lebanon through organ and tissue donation and transplantation</li> <li>increasing the organ and tissue donation rate to reach self-sufficiency through implementing a Lebanese model for organ and tissue donation and transplantation</li> </ul>
Key success factors (KSFs)	<ul> <li>Increasing the organ donation rates</li> <li>Establishing a national organ donation laboratory</li> <li>Reaching self-sufficiency in organ donation</li> </ul>
Organization structure	<ul> <li>PPP (MoPH &amp; NOD-Lb)</li> <li>Board</li> <li>Coordination at 3 levels (national, regional, hospital)</li> </ul>
Strategies & plans	Not available at the moment
Key performance measures (KPMs)	<ul> <li>Number of transplantations by source &amp; organ</li> <li>Conversion rates</li> <li>Number of patients on waiting list</li> <li>Number of donation cards</li> <li>Family consent rates</li> </ul>
Target setting	Internal, Organ donation rates of 20 donors/million Inhabitants by 2020
Performance evaluation	<ul><li>Plan for hospital audits</li><li>NOD-Lb Audited by international agencies</li></ul>
Rewards system	<ul> <li>Not used but to be included in accreditation for hospitals</li> </ul>
Information flows, systems & networks	Adhoc meetings as needed
PMSs use	Not used
PMSs change	Cannot be assessed

Source: author's compilation

It is clear that in the years following the SEUSA intervention, the Lebanese system of organ donation and transplantation was on the right track with donation, conversion and

family consent rates on the rise. The number of organ donation cards increased in accordance with showing higher levels of public awareness and intense organ donation and transplantation related activities. Despite the slight progress in deceased donation, the Lebanese system like other systems in the region continues to be heavily dependent on living organ donors. The qualitative indicators also indicated satisfactory progress. However, the gaps in the PMSs evaluation and the economic and political context of the country were strong deterrents to the evolution of the system.

The following section presents the challenges faced by the organ donation and transplantation system using the governance framework. This should provide a better understanding of the situation and allow an informed analysis from a managerial perspective.

## 4.5. ISSUES WITH ORGAN DONATION AND TRANSPLANTATION IN LEBANON: SERVICE DELIVERY, GOVERNANCE AND SOCIETY

"in May and June 2017 we had seven potential deceased donors with around 50% consent rate. Of the four donors whose parents consented, only four organs and six corneas were used. Five kidneys were refused because of poor maintenance. One kidney was damaged by the car accident. Two adult hearts were retrieved and successfully transplanted whereas two pediatric hearts were not retrieved due to the absence of pediatric patients registered on the national waiting list. Three livers were not retrieved either because they could not be matched to registered patients or

because of financial problems related to the inadequate financial coverage of liver transplantation. One liver was not used because it was damaged in the accident."

-NOD-Lb participant-

This is but a glimpse of the challenges faced with the implementation of organ donation in Lebanon today. All respondents unanimously agree on the importance of the organ donation program given that it addresses the problem of organ shortage and the needs of all patients, not just one individual. However, the rate of donation remains low due to a multitude of factors that are summarized in this chapter.

#### 4.5.1. Service Delivery

#### 4.5.1.1. Delays in the legal process

As in all other countries, the declaration of death is governed by legislative procedures that often cause delays in the organ donation process and add to the burden of the afflicted families and the maintenance team. This wastes a considerable amount of valuable time and might lead to reversal of the donation decision or loss of organs due to unduly prolonged maintenance. The problem is particularly important in Lebanon where on the one-hand the declaration of death is restricted to regular working hours whereas organ donation usually occurs because of an accident and cannot necessarily be governed by time. On the other hand, the process itself is tedious not always clearly understood. For example, a short scenario would start with the coroner filling a report confirming brain death and family consent. However, in medico-legal cases, the coroner cannot complete the process until the parents get clearance from the police to release

the body and the police cannot do so until they get orders from the legal authorities to close the file. Therefore, in practice, the family who is already grieving, tired and eager to have the body released to make the burial arrangements, has to take the file to the appropriate police station. At the police station nothing can be done without the approval of the legal authorities who are only available during regular working hours. Not only that, but the judges who make the decisions to close the file, are not always informed of the laws concerning organ donation and therefore, need time and further explanation to expedite the matter. In addition, there is sometimes confusion as to which police station should actually handle the matter! Should the family go to the one closest to the hospital or the one closest to where the accident took place? Filtering in the traffic situation in Lebanon, the burden of the procedure and the requirement of some religious traditions for quick burial ceremonies (within 24 hours in some cases), the legal issues lead to severe delays in organ procurement which cause loss of organs either through parental reversal of decision or maintenance failure.

#### 4.5.1.2. Delays in the process

There are examples of delays in various steps of the process including reporting of potential donors, informing the parents of brain death and allocating organs. ICU physicians in collaborating hospitals are required to report potential donors. However, some hospitals do not declare their cases while others declare them at the wrong time. Delays in the allocation of organs occur when there is a need for extra cross matching or when the surgeon is unavailable. Allocation is based on a point system that is run manually while awaiting the appropriate software. Furthermore, if a surgeon is absent, a

replacement needs to be found or his patients cannot get transplanted and the organs need to be reassigned and the patients rerouted. Finally, there have also been cases of delays in prepping the operating room.

#### 4.5.1.3. Poor communication with the parents

Hospital coordinators are appointed by the hospitals and sometimes despite their training, the person talking with the parents is not up to the task and family consent cannot be obtained. It is important to detect and monitor these cases and to conduct on the spot evaluations so that they are shown the errors of their ways are allowed a chance to improve. Moreover, some hospitals refuse to appoint a coordinator from the ICU who would in essence be directly in contact with the patients. Instead, they chose to appoint an administrator for the task which limits communication as he/she wastes time going back and forth to get the necessary information. Administrators are also more likely to be on a 7am-3pm schedule and will not accommodate the constraints necessary for the organ donation process. For example, in one particular hospital where the coordinator is an administrator, referral usually comes at a standstill right after activation as the coordinator stops contact with the NOD-Lb office outside working hours.

#### 4.5.1.4. Inefficient organ maintenance

There are cases where the medical work is not being done properly and the reanimation protocol is not meticulously applied or suggestions from the coordinator are not taken into account.

"Often, we are called for a deceased donor where the family has accepted donation.

When we contact the intensivist, we find out that the maintenance has been so bad that the organs have been lost, Last year we lost 4 donors because of poor maintenance.

This is really now something unheard of ... now we have people that are saying yes but the medical work has not been done properly!"

- NOD-Lb participant -

#### 4.5.1.5. Incomplete waiting lists

The problems with the waiting lists are two-fold. First physicians have to approve patients and direct them to the NOD-Lb offices so they are included on the waiting list for a particular hospital. However, some physicians working under the assumption that the process is too lengthy and is therefore not worth the effort and anticipation, fail to enroll their patients. This minimizes the chances of these individuals receiving the needed organs. On the other hand, some physicians register their patients even when the hospital they belong to has stopped the program. In these instances, in case of suitable organ availability, these patients have to be transferred to another surgeon who works in a hospital that is still part of the program.

The other aspect of the problem with the waiting list is that transplant centers should continuously follow-up with the patients on the waiting list to update their files with new information and up-to-date test results. However, this task is more often than not left to NOD-Lb.

"If we do not follow-up with the patients the files do not get updated.

- NOD-Lb participant -

#### 4.5.1.6. Incomplete reporting on the procedure

In addition, reporting is not standardized across hospitals and in some cases poorly kept with some details skipped over or improperly recorded. This makes a review of the process difficult especially if there have been problems and complications. It is tough to implement quality control when there are no records or those available are not transparent.

"Files are not well documented and incompletely updated"

- NOD-Lb participant -

#### 4.5.1.7. Unstandardized mechanisms for resolving problems

Problems are dealt with on a case-by-case basis always under crises and in emergency situations. Solutions are punctual, proposed on the spur of the moment to deal with obstacles as they arise. Most solutions are based on interpersonal relationships and the concerted efforts of the NOD-Lb team. There is a need for a more strategic vision to ensure long term solutions such as putting some pressure on hospitals through prioritizing organ donation, supporting the process, implementing the rules without fail, and giving hospitals incentives to participate, in the form of accreditation or budget allocations as suggested by NOD-Lb in the new regulations that are awaiting the

approval of the council of ministers. Hospitals will only impose stricter rules on personnel, equipment and the general flow of the process, if they are motivated.

#### 4.5.1.8. Conflicting hospital policies

Since the organ donation process occurs mostly within the hospital it is subjected to the rules and regulations of the specific hospital. Sometimes these rules conflict with the organ donation requirements and hinders the process.

"...but there are things that are not in the hands of the personnel in the ICU or the coordinator, they are more administrative, there is a policy in the hospital that we cannot do this we should do that"

- NOD-Lb participant -

#### 4.5.2. Governance and regulation

#### 4.5.2.1. Outdated and loosely formulated laws

The laws and decrees themselves are not always clearly formulated which leaves room for different interpretations and difficulties in implementation. Added to that, with time they have become outdated and incomplete. Some of the subsequent decrees cancel out previous decrees however, due to the way in which they are written or were proposed, not all of them are recognized by the Lebanese court of law.

"We are working with the old law but the gaps in the law are addressed by ministerial decrees. There are some 10 decrees to cover the gaps in the law. Why not have a complete well-written law?"

- NOD-Lb participant -

Since most of the process occurs within the private sector, there is a need for a more efficient legal mechanism to control the hospitals and physicians. The law as it stands formalizes the process and spells out the role and duty of NOD-Lb but it does not extend much beyond that to assist in the implementation of the process.

"Requires rules and regulations from the government forcing them [the hospitals) to do all these changes and these for the time being do not exist. We have to work on everything from scratch"

- NOD-Lb participant -

One proposed solution is to incorporate organ donation within the hospital accreditation system which is already in place. If the hospital accreditation is adjusted to take into account organ donation practices in the scoring mechanism, this would provide hospitals with an incentive to participate and run the process efficiently.

"... but when they see that with the accreditation these things [not implementing the process properly] will obstruct their certification and make them lose their bonus, I think they will do all of these correctly. That is why the law..."

- NOD-Lb participant -

#### 4.5.2.2. A fragmented health system

The health system in Lebanon is heavily fragmented with a predominantly private service delivery and a public sector with a weak regulatory presence. In such a system, the government has little direct authority over the hospitals or the physicians. Therefore, the only incentive for either to do a proper job is their own ethical standards and altruistic tendencies and desires. In a free-market economy where institutions and individuals are constantly competing these are unlikely to weigh very heavily in the balance. The process of organ donation is complex and takes time that could be allocated to a more lucrative endeavor. Therefore, unless the team is personally committed to the process, they will not carry out the procedure properly. This is one of the reasons for poor maintenance of the organ in some centers. As a result, some surgeons have no trust in the process and sometimes refuse to continue with the transplantation procedures for fear of poor results.

"In Lebanon, medicine is private, [...] They lose 3 or 4 hours of clinic income money so they do not come"

- NOD-Lb participant -

#### 4.5.2.3. Lack of financial support

The financial constraints are one of the main problems cited as they appear to have repercussions on all aspects of the donation process.

"The main problem is that NOD was not given the financial capabilities to continue the program properly.... it [the program] was supposed to give tremendous results if it was given the necessary financial backing."

- NOD-Lb participant -

Financially, NOD-Lb relies heavily on a budget allocated by law by the MoPH. The budget is assigned on a yearly basis depending on the political and financial situation of the country and the extent of the MoH's support. Not only is the budget not a fixed quantity but in general, it does not cover the running costs of the program let alone account for any promotional activities. Everything costs money and the lack of it reduces the incentive for participation on the part of both the hospitals and the physicians. As explained by one respondent,

"The hospital directors have a problem; even if they want to help us and many of them really want to help us, they have to face the fact that they might not be adequately reimbursed for the services they are offering. In regard to their hospitals, if they spend money that they cannot recuperate, it does not look good."

- NOD-Lb participant -

In addition to the quantity, there is a major problem with the timely disbursing of the budget which more often than not gets caught up in the multiple rapid changes of government and ministries which in turn lead to delays in the setting of the yearly budget. The government is well-known for delays in payment which again demotivates collaboration on the part of the stakeholders who have to wait a long time to be reimbursed.

There are also reports of inconsistencies in accounting whereby some surgeons and hospitals claim that they did not get the promised compensation. This situation again discourages collaboration as again stakeholders are concerned about not getting paid for their services. It is hard for NOD-Lb to keep track of the process since the payments are transferred directly to the hospital and the physician's accounts and NOD-Lb are kept out of this particular loop.

Due to various billing and financial issues, there are hospitals who refuse to take patients subsidized by the MoH. In such cases, the organs have to be reallocated in a short period of time so as not to lose them. It is not always easy to find another match that can be admitted to the hospital using another funding scheme.

Moreover, to retrieve the funds, which are disbursed by the Governmental Audit Court, the organization needs to justify their expenditures and present the bills. This suggests that the budget is, therefore, disbursed after it has been spent which means that the accounts of the organization tend to be continuously in deficit.

Other than paying the employee salaries and the services of hospitals and health personnel, additional expenditures include money allocated to awareness campaigns, continuous education courses and seminars and conferences in schools, universities and private institutions.

#### 4.5.2.4. Deficiencies in materials and infrastructure

The unpredictable nature of the organ donation process makes it very difficult to stock up on and keep track of the needed materials. Some hospitals for example would not have the proper surgical string necessary to finish the job or enough preservation solution as required by the process. In such instances, the process depends heavily on the surgeon performing the transplantation. He is required to come prepared with all items necessary to complete a successful donation procedure. However, in practice, that is not always the case and the team has had to face situations where "the doctor arrives with 1L of solution when he knows he will need 2". In such a situation the solution has to be used sparingly or the coordinator has to scramble to find more.

Another example includes the doctor coming without sterile ice knowing that the hospital does not stock.

Other aspects of this problem that make the logistics of the process even more difficult are poor inventory. Materials are not always properly accounted for and NOD-Lb is not always informed of missing materials in a timely manner. The most extreme example would be an instance where all the hospitals ran out of the preservation solution. Since

this was only discovered at the time of organ retrieval, the NOD-Lb administration had to use personal contacts to ensure solutions.

Many hospitals are old and in need of upgrading their facilities and equipment. For example, hospitals that are interested in corneal retrieval, need to refurbish their morgues to be able to participate in the process. Moreover, hospitals need to allocate an appropriate space to allow communicating with the parents.

#### 4.5.2.5. Scarcity of human resources

The process of organ donation and transplantation requires specialized teams that need to be continuously trained and committed to the process. Unfortunately, there is a high turnover both internally and externally. Health professionals that are trained to be part of the organ procurement process keep changing their roles within the hospital and more often than not, in their new roles, they are no longer involved in the routine activities surrounding the process but rather take on a more supervisory position. For example, in one hospital it was discovered that 90% of the group that was trained 3-4 years ago, have changed their positions and are not doing the same job anymore. This results in the need to train others which requires both money and time and needs to be planned and budgeted. Therefore, it is important to keep training coordinators on a yearly basis. Furthermore, it is also important to convince the hospitals of the necessity of these training efforts.

"Usually, we have tried to train mainly people from ER and ICU and we discover after 1

year that they have been moved to other services where their participation [in the

donation process] is really much less fruitful; their participation in the project becomes

very limited"

NOD-Lb participant -

There is a scarcity in human resources and hospitals that do not have a trained team need to allocate entry-time to introduce the team, program paperwork and engage in the process. For example, at present, there is only one transplant surgeon per unit.

Consequently, when the surgeon is absent or unavailable, his patients cannot get transplanted. Time of retrieval is always a problem and physicians always want to negotiate for a more suitable time which is unfortunately not possible. This is especially problematic when the transplant surgeons are older. They might not be up for retrieval at odd hours and will therefore, not respond to calls. Moreover, there are hospitals that share physicians among them which additionally hampers the process. In some cases, the same team retrieves and transplants the organs and they have to move from one hospital to the next. It is important to remember that the health professionals concerned with the organ donation and transplantation process already hold full-time responsibilities and their contribution consists an added burden for which they are not always well-remunerated.

4.5.2.6. Inaccuracy of media reporting and transmission of information

The media plays an important role in the process of organ donation which can be have both a positive and a negative impact. For example, programs that portray organ donation in a positive light and offer scientific information provided by experts in the field have had the capacity to increase the number of donation cards submitted to 500 demands in the space of half an hour as opposed to the 1000 submission in a usual year. In the same vein, programs that focus on organ trafficking and shady behavior have the exact opposite effect and the repercussions on the organ donation process are immediate and difficult to absorb and manage.

Media involvement is important to promote awareness and transparency but reporters should be better trained to investigate and check their stories, facts and sources. In Lebanon, there is no control over the media or censoring on their programs. There are also no sanctions or repercussion for misinformation or fraudulent acts. Given that reporters are always in search of scoops that tend to distort rather than reinforce the image of organ donation, NOD-Lb has to be extremely vigilant and keep a tight rein of control on the information diffused. Social media has the same effect but it is easier to control as it can immediately be addressed without going through bureaucratic mechanisms.

#### 4.5.2.7. Lack of stability, continuity and commitment

In order to be efficient, the organ donation process requires commitment, stability and continuity. It cannot be run on a voluntary basis, adhoc basis or turned on and off at will.

Unfortunately, the political situation in Lebanon has not helped the process. Given that final approval is contingent on the MoH, it is very difficult to involve him in the process when he keeps changing every few months. Moreover, every time the MoH changes, the process of organ donation stops as the team has to reorganize itself and adapt to the requirements of the new MoH. In addition, there are long gap periods where there is no government which means no promulgation of new laws or issuance of ministerial decrees.

"It is a long procedure that's why it needs to be on a continuous basis and we are unable to provide a continuous service"

- NOD-Lb participant -

"Our service is continuously interrupted"

"the ministry changed and the law was not voted, waiting for the new ministry"

- NOD-Lb participant -

Moreover, most MoH did not support the project nor give it its rights. In fact, they blocked its activities, its budget and did not pay attention to the needs of NOD-Lb except when they wanted to bypass the regulations of living donor transplants.

#### 4.5.2.8. Presence of corruption

Although considerable efforts have been invested in avoiding corruption, some parts are inherent to the Lebanese culture. It appears in the form of taking shortcuts and

bypassing the agreed upon procedure, dispensing bribes to government officials and using emotional appeals to the MoH with whom the final decision lies. There have also been some concerns about coercion of living donors but the ethics and medical committees have been vigilant in that respect. In addition, there is considerable waste of public resources which is frustrating as organ donation is severely underfunded.

"When you see the amount of waste in the country and all you are asking for is \$300,000-400,000 it is not this humongous sum. If they give us \$600,000 we would excel, our demands are limited."

- NOD-Lb participant -

A more concrete example of power abuse and corruption occurred in 2020 when the MoH of a resigned cabinet decided to implement changes by separating the administrative and medical directions and changing some of the board members. These changes were not voted on by cabinet (as per the law) and therefore were not officially recognized. However, in practice the changes were adopted and implemented by the said MoH and his successor (of the same political party).

#### 4.5.3. Society and culture

#### 4.5.3.1. Health professionals that are not supportive

The clinical/administrative staff involved in the organ donation process "do not always cooperate" and physicians in particular "do not appreciate interference from non-physicians". Physicians do not enjoy receiving guidance from nurses and administrators, even if it is part of the latter's job descriptions. On the contrary, some take offense when asked to submit to the supervision process and refuse to respond when questioned. This makes the local in-hospital coordinators' job harder and demotivates them. They minimize their interference, do not call physicians out and evade the check-up process. As a result of these poor dynamics, the whole process suffers in certain hospitals.

The healthcare professionals are not always committed to the idea of organ donation. They often forget to inform parents of potential donors of the possibility of donation, do not conduct proper maintenance because of some preconceived notion, or try to negotiate the time of retrieval. Given that organ donation is more often than not an unplanned event the time of retrieval is usually not predetermined and not set at the doctor's convenience.

The doctor-nurse relationship is another aspect of organ donation that is heavily entrenched in cultural norms. The physician has a special status in Lebanon and is usually considered the accepted reference in all health-related issues. Nurses, on the other hand are seen as subordinates to the physician. Given that the coordinators tend

to be nurses and that they behave as overseers of the process and sometimes need to advise or order the intensivists around, this results in a difficult working arrangement. Not only that, but the gender difference also plays a role in this interaction as nurses are still predominantly women while physicians in these particular domains tend to be men again subjecting the process to unnecessary tensions due to stereotyping and the patriarchal configuration of the Lebanese society.

#### 4.5.3.2. Religion as a barrier

Religion is heavily embedded in all aspect of Lebanese life. In fact, issues such as death, marriage and inheritance are governed by the religious rather than civil courts. Even though NOD-Lb has strived to make public the endorsement of the religious leaders of all sects, it is not always enforced at the local or regional level. Religious figures have a major impact on the decision-making process of parents of potential deceased donors and appear at times resistant to the process or hesitant in their advice. Furthermore, the health professionals themselves are often torn between medicine, science and their own beliefs. In such instances they find it very hard to promote organ donation at work when personally they believe it to be against their faith.

#### 4.5.3.3. A public that is not informed or committed

The lack of commitment and cooperation that is often experienced is also a result of societal and cultural beliefs. Despite all of NOD-Lb's work and promotional efforts, organ donation is not yet seen as a priority by the community at large and the public

does not feel concerned with this issue. In fact, they only show sudden interest when there is a need. Some people do not even know that such a program exists in Lebanon.

#### 4.5.3.4. A tradition of self-interest and favoritism

As is the case with the provision of services in general, some individuals believe that they are above the law and that rules and regulations are not for them. These individuals are continuously on a quest for ways to bend the law, obtain favors and beat the system. Organ donation and transplantation is no exception to this rule as NOD-Lb frequently has to direct people to follow the rules and respect the law without exhibiting any favoritism.

### 4.5.4. Challenges of governance in the Lebanese context: Archaic laws, fragmentation and corruption

The problems presented in the previous section are summarized in table 4.6 based on the governance framework proposed by Mikkelsen-Lopez et al. (2011). It is clear from looking at the table that the organ donation and transplantation system in Lebanon suffers from a wide variety of problems at all levels. In terms of service delivery, delays due to various reasons are critical to the system as a whole since time is of the essence in this process and the organs cannot wait to be retrieved or transplanted. Part of the complexity of the system is the time issue over which there is very little control. The fact that solutions to delivery issues are more or less adhoc is another problem that points to the continued use of personal solutions that lack a consistent mechanism to deal with problems as they arise. The problems on the societal level seem to be common to most

organ donation systems and can probably be reduced through awareness campaigns and education. The governance problems however, remain the most prominent as they require considerable adjustment and commitment in order to bring about legislative changes, health sector reforms, financial security, resource availability and dissemination of information. In fact, it would appear that both the delivery and the societal problems could be resolved through working on the governance issues.

Table 4.6: Issues with organ donation and transplantation and their consequences in Lebanon

Governance Framework Level	Problems	Consequences
Service delivery	Delays in the legal process Delays in the process Poor communication with the parents Inefficient organ maintenance Incomplete waiting lists Incomplete reporting Conflicting hospital policies Unstandardized problem solving mechanisms	Loss of viable organs Refusal to donate Hinders evaluation Weak collaboration Low donation rates
Governance	Outdated and loosely formulated laws A fragmented healthcare system Inadequate financial support Deficiencies in materials and infrastructure Scarcity of human resources Inaccuracy of media reporting and transmission of information Lack of stability, continuity and commitment Presence of corruption	Slow development Reduced donation and transplantation activities Reduced trust in public authority Blocked decision-making process Bottlenecks Inequality in access Low donation rates
Society	Lack of support from health professionals Religion Lack of information and commitment from the public Self-interest and favoritism	Low donation rates

Source: Author's compilation

## 4.6. THE LEBANESE PPP FOR THE GOVERNANCE OF ORGAN DONATION AND TRANSPLANTATION: A HYBRID SYSTEM

The Lebanese system of organ donation was created as part of a fragmented healthcare system within a fragile context fraught with uncertainty at various levels. Politically, the country was still recovering from a civil war that lasted 15 years and left it devastated while economically Lebanon had lost its intermediary role in the region and was facing inflation, the degradation of public services, and the destruction of infrastructure including health, water, sewage and power (Kronfol & Bashur, 1989). Moreover, the country experienced severe brain drain due to the exodus of its human resources. The health sector mirrored the situation in the country and emerged from the war with a weak and fractured public sector and a dominant private sector that was paradoxically, financially dependent on the public sector. Clearly, as discusses on chapter two these are all reflections and consequences of the fragmentation of the healthcare system and the fragility of the context in which it operates (Hill et al., 2014)

In a fragmented healthcare context, and due to the will of a few concerned specialists the system of organ donation in Lebanon was established. It was developed in the spirit of New Public Management as a public private partnership based on collaborative governance policy reforms undertaken by the MoPH. This partnership was driven by a civil society initiative and based on a relational contract with the government that in essence merely served to establish the regulatory agency (NOD-Lb) as an autonomous private entity in charge of implementing the organ donation process in collaboration with

the MoPH which serves as the legislator. The regulatory agency and its governing body were appointed by law. In fact, these were only allowed to change by Ministerial decree.

In practice, the Lebanese system of organ donation and transplantation appears to be a hybrid system that combines different elements in order to adjust to the particular context in which it was developed. Similar to the US system, the regulator is a private entity that runs autonomously. In fact, NOD-Lb appears to combine the functions of the OPTN, UNOs and OPOs all in one organization. However, whereas these organizations are privately financed depending on the government for only 15% of their funds, NOD-Lb, similar to the other three systems surveyed, is publicly funded from a budget allocated by the MoPH that fluctuates depending on the MoH and the current situation of the country.

The Lebanese system, like so many others, is modeled after the Spanish Model of organ donation and transplantation with its tripartite coordination system that functions at three levels namely, national, regional and local (*Consultancy in Organ Donation | TPM – DTI Foundation*, n.d.). NOD-Lb has invested extensive efforts in training local coordinators appointed by the hospitals as well as regional coordinators to oversee them. However, the health system in Lebanon is not as clearly decentralized as that of countries who have adopted this coordination strategy. Therefore, although NOD-Lb acts as a central office like the Spanish ONT or the *Agence de la Biomédecine* in France, its duties go beyond national coordination to encompass the roles of the regional and even the local coordinators. This could be a function of the size of the

country which is small enough to cover in a few hours pending weather and traffic conditions. Another explanation could lie in the fact that the organ donation system in Lebanon is not mature enough to be trusted to function independently. In the Spanish system, local coordinators are empowered and held responsible for the whole process from donation to transplantation including approaching the family and talking to the media a task for which they are trained. In Lebanon, due to understaffing, lack of commitment and limited financial resources, NOD-Lb plays most of these roles or at least is always present in a supervisory capacity. In addition, whereas in Spain, policies are developed by the Transplantation Commission of the Health Inter-Territorial Council which consists of the national coordinator, the regional coordinators and the state, in Lebanon, they are mostly developed by NOD-Lb after consulting with the regional coordinators and proposing them to the MoPH. It is interesting to note that in countries like the US and France, even the public is actively involved in the development of the organ donation laws with platforms set-up to allow people to comment and discuss policies as they are being considered.

It is already clear from studying the Spanish and the French systems, that a performant coordination system is not enough. A successful organ donation process is contingent on a holistic approach that combines efficient coordination with a positive societal attitude, the support of the healthcare personnel and the commitment of the government (Manyalich et al., 2011; Matesanz, Domínguez-Gil, et al., 2011; Matesanz et al., 2017). The Spanish have a whole philosophy to embody the act of organ donation which is described as the vital cycle which starts and ends with society (Manyalich et al., 2011).

Similarly, the French system is highly contingent on the solidarity of its citizens. In this vein, both countries have adopted opt-out policies whereby citizens are presumed donors unless they declare otherwise. Lebanon, like the USA and Turkey have opt-in systems in place where citizens or their next of kin need to declare their will to donate. Not only that but analyzing these systems through the PMSs framework points to the fact that they use performance management tools and methods to evaluate and enhance the performance of the system. This is one aspect that requires further development in the Lebanese system.

With the exception of the USA, organ donation in the countries reviewed is run by a public agency that is part and parcel of the Ministry of Health which acts as an active investor and contributor to the process. Unlike these systems, the state in Lebanon mainly provides the legal umbrella by approving and ratifying laws without actually providing the power to enforce or modify them. Therefore, whereas NOD-Lb is in charge of implementing the process of organ donation it is not given the necessary tools to do so. NOD-Lb is mandated by law and is legitimized by public funds but in the eyes of the public it is still a private entity. Moreover, given that the Lebanese health system is mostly run by the private sector and that the government has little control over the hospitals and by transition the physicians, this leaves the regulator very little leeway in terms of ensuring their cooperation. Even the accreditation system, which is seen as a way to encourage hospitals to conform with the organ donation directives for the country, has been slow in the making and has yet to be applied. Added to that is the matter of reimbursing the hospitals and physicians which again in a system mostly run

through private insurances, out-of-pocket payments and delays in governmental reimbursement leaves little room for willingness to participate in the process. Another important consideration is the lack of a national strategic plan with respect to organ donation and transplantation in Lebanon. This could be explained by the ambiguity of NOD-Lb's status as the preparation of the strategic plan appears to be led by the ministry in the public healthcare systems like Spain, France or Turkey, or the private regulating entity like in the USA. However, given that NOD-Lb considers itself a public entity whereas the ministry sees it as private, it is not surprising that there is no formal strategic plan to guide the performance management of organ donation in Lebanon. Given its location and culture, the Lebanese system appears to have more in common with the Turkish system. Both countries depend heavily on living donation rates while deceased donation rates remain relatively low. The two countries have high power distance and religion plays an active role in the decision-making process. In fact, the latter is thought be one of the major barriers to full endorsement of organ donation by the population. Although the religious leaders have been vocal in their support, doubts still remain. Local clergy and healthcare personnel are heavily influenced by their own interpretation and understanding of what is religiously and ethically acceptable. Given their role in these societies, it does not come as a surprise that their attitudes should have a major impact on donation and transplantation rates. Unlike Lebanon, however, the governance of organ donation and transplantation in Turkey is embodied in a unit within the Ministry of Health and follows the example of Spain and France by exerting more regulatory control over the process.

Similar to the situation in Lebanon, organ donation efforts in Turkey began at the individual level. However, whereas the State has since taken over in both countries, the results in Lebanon remain timid. To be fair, the government in Lebanon has been so involved in its political and economic struggles that organ donation has been put on the back burner again an indication of the lack of real commitment to the cause. As one respondent from NOD-Lb mentioned, NOD-Lb has failed to convince the government of the real importance of organ donation and therefore, the concept remains more of a luxury than a necessity in their minds. Whereas the MoPH has been actively involved in promoting awareness for mental health and other non-communicable diseases including cardiovascular diseases and cancer, it has been relatively silent on the issue of organ donation (*MoPH*, 2022). Even the Lebanese society remains removed from direct involvement in the process as, despite all the awareness campaigns undertaken by NOD-Lb, a large portion of the population does not know that there is an organ donation program in Lebanon. Some of the burden also falls on the shoulders of the healthcare personnel who in the majority, have not embraced this program. Physicians especially seem to be disinterested or do not have the time to engage in the process. Again, it is important to remember that the healthcare system in Lebanon is private and time spent on organ donation activities is time spent away from more lucrative pursuits. Unlike, the Spanish system where physicians are hired for part-time organ donation duties, the Lebanese physician is not properly remunerated for participating in organ donation activities.

Finally, it is important to remember that studies on organ donation have stressed the importance of a stable political environment and adequate financial support. In fact, one of the main proponents of the SEUSA program is to prepare the field prior to embarking in an organ donation program. These two conditions which are guaranteed in the four models reviewed in this thesis are lacking in the Lebanese context.

Most of these problems in fact seem to stem from the fragmentation of the system, the fragility of the context and the Lebanese culture (Hill et al., 2014). Given that the main problem with the Lebanese system of organ donation and transplantation lies in the governance of the system, the last part of the thesis will concentrate on this aspect. More specifically, the next chapters will address the role of NOD-Lb in regulating the organ donation and transplantation process, the characteristics of the PPP between NOD-Lb and MoPH and finally revisit governance from the perspective of interorganizational controls.

## PART III: A PPP-BASED PERFORMANCE MANAGEMENT MODEL FOR ORGAN DONATION AND TRANSPLANTATION IN A FRAGMENTED HEALTHCARE SYSTEM IN A FRAGILE SETTING

Now that there is clear evidence that governance is the main issue relative to the performance of the organ donation and transplantation system in Lebanon, the objective of this next and final part, part III, is to analyze the PPP-based model from three performance management perspectives, regulatory agency, governance and interorganizational management controls. This part is divided into two chapters. Chapter 5 answers the third research question, namely "How can a PPP-based governance and regulation solution to the performance management issues of organ donation and transplantation be analyzed?". Chapter 6 answers the fourth and final research question: "What could be the contribution of interorganizational control literature to address PPP-based governance and regulation issues for organ donation and transplantation?"

# CHAPTER 5: ANALYZING PPP-BASED REGULATION AND GOVERNANCE MODELS

This chapter focuses on the PPP between NOD-Lb and the MoPH from two perspectives: the regulatory role of NOD-Lb and the characteristics of the partnership between the MoPH and NOD-Lb. The first part of the chapter analyzes the regulating body, NOD-Lb, in the context of the NPM perspective by situating its characteristics within the agency and stewardship theories. The section part of the chapter will exploit a framework proposed by Asquith et al. (2015) to explore the nature of the contract and the partnership that exists between NOD-Lb and the MoPH in terms of the relationship, trust, commitment and stability of the PPP (Asquith et al., 2015). J. M. Brinkerhoff's (2002) partnership model with its focus on mutuality and organizational identity will be used to investigate the relationship.

#### 5.1. NOD-LB: BETWEEN AGENT AND STEWARD

NOD-Lb has the capacity to operate as an Independent Regulatory Agency (IRA). NOD-Lb in its role as coordinator for and supervisor of the National Organ Procurement

Network and its activities, enjoys IRA status and has well defined powers which afford it the authority to implement the organ donation and transplantation process, make informed decisions and propose legislature. At the administrative level it has taken on the role of overseer controlling and solving problems as they arise, routinely inspecting hospitals, maintaining patient files, following up on daily transplant activities and basically stepping in whenever and wherever needed. This regulatory body is governed by a hierarchical structure and a board, is allocated a budget and has decision-making

freedom at the administrative level. It is bound to the MoPH by legislature, through a collaborative governance scheme with no control mechanisms.

#### 5.1.1. Regulatory agencies: agencification or. stewardship

The application of NPM doctrines (Musa & Petak, 2015; Peters, 2013) has led to the rise of independent regulatory agencies (IRAs) (Badran, 2012; Gilardi, 2002; Thatcher, 2002) in an attempt to increase the integration of complex systems in various sectors (Fernández-i-Marín et al., 2016; Maggetti, 2014; Musa & Petak, 2015; Peters, 2013; Zenginobuz, 2008) by bringing the decision-making processes closer to the users. The creation of IRAs with the intent of increasing efficiency and protecting the interests of consumers and citizens (Çetin et al., 2016; Christensen et al., 2008; Kim & Cho, 2014; Zenginobuz, 2008) through delegated governance rather than direct centralized intervention (Coen & Thatcher, 2008; Lægreid et al., 2008), has resulted in specialization of functions, fragmentation of state administration and political decentralization and therefore, raises a crucial need for coordination (Musa & Petak, 2015; Peters, 2013). This is especially true in countries in transition where the development and institutionalization of "coordination structures and functions which would connect government horizontally and vertically and ensure transparent and effective decision making and implementation" (Musa & Petak, 2015, p.118) becomes even more necessary.

Defining IRAs appears to be a challenging task as the literature offers an abundance of definitions (Badran, 2017; Lægreid et al., 2008; Sulle, 2010; Thatcher, 2002). This could

be due to the fact that the specification of agency, autonomy and regulation are contingent upon the particular country and its political system (Jordana et al., 2011; Sulle, 2010; Thatcher, 2002). Agency, in its narrowest sense, is defined by Pollitt and associates as "a structurally disaggregated body, formally separated from the ministry, which carries out public tasks at the national level on a permanent basis, is staffed by public servants, is financed mainly by the state budget, and is subject to public legal procedures" (Christensen et al., 2008; Lægreid et al., 2008). In fact, different agencies could serve different functions and benefit from different levels of independence. Agency responsibilities could vary from regulation to managerial tasks to the provision of services or policy advice.

Regulation, like agency, is also an ambiguous concept that can be used in both a broad and a narrow sense (Jordana & Levi-Faur, 2004). Most broadly, regulation can be thought of as any form of social control whether intentional or not. This form of control could encompass the public institutions as well as the private ones. The more confined definition, on the other hand includes the process of goal setting, rule-making, monitoring, evaluation and enforcement, in the perspective of behavior-modification (Lægreid et al., 2008).

IRAs are legally empowered (Epstein et al., 2009) and enjoy some level of autonomy but might not be totally independent. The level of autonomy of an agency is contingent on its decision-making competencies on the managerial and policy matters of the agency, but also on the extent of government constraints that can be exercised to curb

these skills on a structural, financial, legal or interventional level (Zenginobuz, 2008). Regardless of the level of autonomy, agencies are specialized entities that are entrusted with specific tasks (Lægreid et al., 2008; Zenginobuz, 2008) and therefore could require particular levels of expertise that are not necessarily within the realm of a public servant. In contrast with the latter, IRA members have the distinction of not being elected by the people or managed by elected officials (Gilardi, 2002; Lægreid et al., 2008; Thatcher & Sweet, 2002). Since this paper is primarily concerned with agencies of private citizens rather than public servants, a broader definition of IRAs, offered by The Better Regulation Task Force (2003) which defines an IRA as "a body which has been established by act of parliament, and operates at arm's length from government and which has one or more of the following powers: inspection, referral, advice to a third party, licensing, accreditation, or enforcement" (Badran, 2017) will be used.

Given their widespread application especially in the USA and Europe, IRAs have been extensively studied from various perspectives including their creation, diffusion, autonomy, accountability, efficiency and performance (Christensen et al., 2008; Coen & Thatcher, 2008; Gilardi, 2002; Jordana & Levi-Faur, 2004; Maggetti, 2014; Thatcher, 2002). However, these studies have been conducted in a limited number of countries, sectors, and regions (Jordana et al., 2011) and few studies to-date have investigated the creation, autonomy and performance of IRAs in less industrialized countries (Badran, 2012, 2017; Çetin et al., 2016; Nchukwe & Adejuwon, 2014; Sezen, 2007; Sulle, 2010; Zenginobuz, 2008).

The complexity of the process and the multitude of stakeholders involved in organ donation and transplantation have led countries to devise national coordination systems with varying approaches and methods for organ procurement taking into account the countries' structures and cultures (Kazemeyni et al., 2009). Therefore, the characteristics of the regulatory agent will first be analyzed through an agencification lens and then enhanced in a further step using the stewardship theory.

#### 5.1.1.1. Agencification

Agencification consists in the creation of specialized autonomous or semi-autonomous agencies in an attempt to separate the implementation function of a body from its policy-making one thus giving the agency a more managerial than bureaucratic orientation (Christensen & Lægreid, 2007; Nchukwe & Adejuwon, 2014). Increasing an agency's autonomy and professionalism should decrease ministerial interventions and allow decisions to be based on empirical evidence and expert opinions rather than political agendas (Christensen & Lægreid, 2007). In such a system, input control would be replaced by output accountability including contracting, financial incentives, and greater competition (Kim & Cho, 2014).

Driven by the NPM paradigm that attempts to bring the private and public sectors closer by decentralizing and transferring managerial and institutional autonomy to private entities (Nchukwe & Adejuwon, 2014), it is believed that the managerial autonomy that IRAs are afforded will enable them to enhance their performance in determining financial and human resource matters (Kim & Cho, 2014). These assumptions are based on the principal-agent theory which postulates that the principal (the state)

chooses to delegate to another actor (IRA) the task of regulating a particular area of public interest (Christensen et al., 2008; Kim & Cho, 2014). There are several reasons for this delegation that are in line with the aims of agencification, and in fact Gilardi (2005) identifies nine including expertise, flexibility, decision-making costs, credible commitments, stability, economic efficiency, public participation and transparency, blame shifting and political uncertainty (Badran, 2012; Zenginobuz, 2008).

The agency theory, which focusses on the issue of control of the agent by the principal due to diverging goals, comprises of three key elements namely, structural separation, managerial autonomy and managerial accountability (Nchukwe & Adejuwon, 2014; Pollitt et al., 2004; Sulle, 2010). Structural disaggregation or separation consists of formally or legally creating autonomous, task-specific organizations with formal goals, an independent budget and accountability arrangements (Sulle, 2010). Agencies can be legally created through legislature, executive orders, decrees or constitutional requirements (Nchukwe & Adejuwon, 2014). Managerial autonomy is a multidimensional construct that reflects the ability of agencies to make their own decisions in terms of goal-achievement, human resources, financial management, monitoring and reporting (Nchukwe & Adejuwon, 2014; Sulle, 2010). Managerial accountability is a mechanism set by governments to control the actions of agencies and ensure the attainment of governmental objectives thus limiting the self-serving goals of individuals. These should be result-based and include setting goals, using indicators to assess results, monitoring and evaluating as well as offering rewards and sanctions (Sulle, 2010).

However, although agencification is meant to have a universal character and should be applicable to all contexts, research has shown that its dynamics vary between countries (Christensen & Lægreid, 2007; Nchukwe & Adejuwon, 2014; Sulle, 2010; Thatcher, 2002). In fact, context matters and since none of the components of agencification are standardized, it cannot be assumed that there is a "best" model of agency that applies to all countries and institutions. Historical evolution, political traditions, policy development and implementation and political leadership are contextual factors that might influence the process and outcomes of agencification (Badran, 2012; Thatcher, 2002). This is especially true in countries in transition where agencification usually implies the creation of new autonomous bodies for new functions (Nchukwe & Adejuwon, 2014; Sulle, 2010). Although agencification in these countries might not be a new concept, it is usually used to counter the corruption of state-owned companies and rarely studied within a systematic conceptual framework. In general, it is driven by foreign advice in a bid for financial aid and is transplanted from other countries without regard to the availability of other elements necessary for the legal set-up especially in terms of legal accountability and financial frameworks. As a result, the latter are irregular, often presented on a case-by case basis to provide a quick solution to unexpected results and negative consequences.

Davis et al. (1997) suggest a series of psychological and situational factors that might explain the need to develop other theories to fully understand the organizational relation between regulatory agencies and the government. One suggestion that has been

brought forward by several researchers is to explore the characteristics of stewardship theory.

#### 5.1.1.2. Stewardship

The premise of the agency theory is that the interests of the principal and the agent are not aligned and therefore managerial accountability is necessary in order to control the agent and limit the losses of the principal (Davis et al., 1997). Agency theory, in summary, deals with conflictual behavior and the tensions that emanate from the limitations of the principal (information, time, resources and knowledge) and the selfinterest and personal motivation of the agent (Schillemans, 2013). The basic tenants of principal-agency theory are conflict and control (Eisenhardt, 1989). In contrast, stewardship theory appears to emphasize trust (Grundei, 2008; Van Thiel & Smullen, 2021). It proposes that there are situations in which the agent exhibits more proorganizational, collective behavior and therefore becomes more of a steward than an agent. Thus, stewardship theory contends that stewards perform based on intrinsic rather than extrinsic motivation and therefore, find self-satisfaction self-realization and personal development as sufficient rewards for higher levels of job performance. Incentives in this case would be offered in terms of praise, and reputation rather than lack of punishment or financial rewards. In addition, stewardship assumes "a low power distance and a personal style of leadership [that] prevents stewards from distancing themselves from their principals and foster[s] bonds of loyalty and respect that decrease the need for control and oversight." (Schillemans, 2013, p.545).

Davis et al. (1997) proposed a model that consists of two main dimensions that explain the predisposition towards agency or stewardship. The psychological and situational components suggest contexts in which organizational relationships would be defined by one or the other of these theories. The psychological factors depict personal characteristics of the agent such as motivation, identification, and power while the situational mechanisms comprise the specificities of the context in terms of management philosophy and cultural diversion. Table 5.1 describes the differences in dimensions between the two theories.

Table 5.1: Psychological and Situational Mechanisms in Agency vs. Stewardship

neones		
	Agency Theory	Stewardship Theory
Model of Man	Economic man	Self-actualizing man
Behavior	Self-serving	Collective serving
Psychological Mechanism	ns	_
Motivation	Lower order/economic needs (physiological, security, economic) Extrinsic	Higher order needs (growth, achievement, self-actualization) Intrinsic
Social Comparison	Other managers	Principal
Power	Low value commitment Institutional (personal, coercive, reward)	High value commitment Personal (expert, referent)
Situational Mechanisms	,	
Management Philosophy Risk orientation	Control oriented Control mechanisms	Management oriented Trust
Time frame	Short term	Long term
Objective	Cost control	Performance enhancement
Cultural Differences	Individualism	Collectivism

Source: Davis et al., 1997

Theories

Rather than choose one theory over the other, Davis et al. (1997) explained that the problems arise when both parties disagree on the choice of relationship. As long as the

High power distance

Low power distance

principal and delegate perceive the same theoretical relationship (agents or stewards) their expectations will align and be met as a result of the collaboration. The problems arise when there is a discrepancy in the roles that each party is expected to play. This is illustrated in figure 5.2. Although this model was specifically developed to describe the relationship between a principle and a manager, it can be applied to different principle-agent type relationships. Other researchers have built on this conception of organizational behavior to propose different models that combine both theories in an attempt to understand the relationship between agencies and central governments (Dicke & Ott, 2002; Schillemans, 2013), management of contracting relationships with non-profit organizations (Van Slyke, 2007), governance mechanisms (Grundei, 2008; Le Tian & Venard, 2012), the role of the supervisory board in the management process (Glinkowska & Kaczmarek, 2015), and satisfaction with governance processes (Schillemans & Bjurstrøm, 2019; Singh & Sirdeshmukh, 2000).

	Principal's Choice	
	Agent	Steward
	Minimize Potential Costs	Agent Acts Opportunistically
Agent	Mutual Agency	Principal Is Angry
	Relationship	Principal Is Betrayed
anager's	1	2
Choice	3	4
Steward	Principal Acts Opportunistically	Maximize Potential Performance
	Manager Is Frustrated	Mutual Stewardship Relationship
	Manager Is Betrayed	neidionalip

Figure 5.1: Principal – Manager Choice Model

Source: Davis et al., 1997

## 5.1.1.3. NOD-Lb as a collaborative governance for a state created non-profit organization

At the time of the inception of NOD-Lb, the Lebanese MoPH was undergoing major reforms following a 15-year civil war that left the MoPH weakened and marginalized within a health sector that was "dominated by powerful lobbies, political clientelism, [and] a booming private sector" (Lerberghe et al., 2018, p.5). In an attempt to reposition itself as a key authority figure within the Lebanese health sector, the MoPH developed its own model of collaborative governance which brought together public and private stakeholders in consensus-oriented networks that included partners that had shared goals and positive track records. Given the fact that the MoPH lacked the instruments

and expertise to apply command and control approaches, collaborative governance was the only sound option at the time.

NOD-Lb was established in Lebanon in 1999 by a ministerial decree (1999, decree 509/1), and designated by the Code of Medical Ethics (No 240- art 30, 2012) as the only official body responsible for supervising and coordinating all organ, tissue and cell donation and transplantation activities in Lebanon. At the time of its conception, given the unstable political situation and the lack of resources, it was not possible to create a public agency responsible for organ donation and transplantation so the alternative was to establish a committee made up of individuals who were concerned with and committed to the issue and interested in investing time and effort to move it forward. With time, the committee became an organization with a framework and budget so that it could function efficiently.

"... it was difficult at the time to create a public agency responsible for organ donation so the choice was to establish a committee made up of individuals (like the MD and NC) who were personally committed in the issue. With time, the committee became an organization with a framework and budget so that it could function."

-MoPH participant-

NOD-Lb as a potential/latent agency issue

5.1.2.

Analyzing the characteristics of NOD-Lb through an agency lens allows the distinction of only two out of the three main components of agency theory namely, structural

separation and managerial autonomy (Nchukwe & Adejuwon, 2014; Pollitt et al., 2004; Sulle, 2010). Managerial accountability, however, is not an issue as can be seen by the analysis below.

#### 5.1.2.1. Structural separation

Established to consolidate organ donation and transplantation efforts into one organization sanctioned by legislature, NOD-Lb provides the expertise necessary to regulate an extremely specialized unit. The ministerial decree (1/65) that drove the conception and delimited the role and responsibilities of NOD-Lb provides institutional distance as the agency is given the sole responsibility of supervising and coordinating all organ donation and transplantation activities pertaining to both deceased and live donation. As per the decree, the organization has its own governing board that is headed by a president. The agency has a separate budget allocated by the MoPH and serves as the Lebanese "face" of organ donation and transplantation both locally and abroad.

### 5.1.2.2. Managerial autonomy

The role of NOD-Lb spans a wide array of responsibilities and functions that enable the organization to benefit from a considerable level of autonomy and flexibility in decision-making concerning human and financial resources as well as operational management. The organization is therefore, free to hire, promote and fire its employees, set salaries and expectations, plan activities, allocate the budget and search for alternative sources of funding. In an effort to further organ donation activities in Lebanon, it can even enter

into contractual agreements with entities it deems important both in Lebanon and abroad.

#### 5.1.2.3. Managerial accountability

Ex post control is a management process that consists of interrelated subsystems mainly planning, monitoring and evaluation (Sulle, 2010). Although NOD-Lb employs these means in an attempt to control the hospitals that are part of the National Organ Procurement Network, it appears as if the parent ministry has not engaged in a similar effort in an attempt to control NOD-Lb. By reciprocity, the performance goals set by NOD-Lb can actually serve to assess its own performance but there is no routine external monitoring or evaluation and no incentives or controls in the form of sanctions or rewards. Since its inception, NOD-Lb has been audited by the Spanish team in 2009 and by the French team in 2013. In 2018, the responsible of the Lebanese project with ABM reviewed all the system before doing a pilot audit in a university hospital. However, as NOD-Lb is funded through public money, a more rigorous mechanism of accountability should probably be put in place.

A possible explanation offered by the DG of the MoPH lies in the fact that NOD-Lb does not, take any bilateral decisions. Since the decision-making process is always overseen by other entities, the MoPH does not necessarily see the need for control in this situation and has not put any measures in place to that effect.

Given the MOPH's orientation towards collaborative governance and consensual leadership and the alignment of the final goals between NOD-Lb and the MoPH with regards to organ donation and transplantation and since there is no need to control the agent in order to ensure that the principal's interests are protected, the principal agent theory does not seem to completely explain the relation between NOD-Lb and the MoPH. This situation reflects other studies that have proposed alternatives or extensions to the agency theory by exploring, for example, the impact of psychosocial and situational factors (Davis et al., 1997; Grundei, 2008; Schillemans & Bjurstrøm, 2019, 2019; Van Puyvelde et al., 2012; Van Slyke, 2007; Van Thiel & Smullen, 2021).

# 5.1.3. Psychological and situational factors that differentiate between agency and stewardship

#### 5.1.3.1. Motivation

NOD-Lb was established in 1999, based on a series of ministerial decrees, in response to a need for a specialized entity that could regulate and coordinate organ donation and transplantation policy formulation and implementation at a time when there was no public agency or civil servants available with the required expertise and skill set. The establishment of NOD-Lb in its present form and structure points to the MoPH's expectation for intrinsic motivation. Rather than contracting out to an already existing body, a new agency was legitimized based on the MoPH's strive for collaborative governance, consensus-oriented networks and consensual leadership. The agency was formed of specialists in the field who had a vested interest in forwarding the issue of organ donation and transplantation and needed a platform within which to work.

NOD-Lb's motivation appears to be altruistic rather than opportunistic and is driven by a strong belief in the process and the need for a national system for organ donation and transplantation. There is no contract with pre specified targets regulating the behavior of the decision-makers at NOD-Lb. On the contrary they appear to be self-reliant and self-motivated continuously working towards the pro social goal of improving organ donation and transplantation rates and processes in Lebanon. Any goals set or achieved are self-proclaimed born out of their excitement at seeing the program through.

NOD-Lb's dedication and perseverance in a climate of administrative, political and financial adversity bears witness to their belief in the process, the system and more importantly the fruits of the collaboration with the MoPH.

"I don't see the reason why small countries in Europe have managed to achieve 30 deceased donors pmp and we [Lebanon]can't achieve 20, 25 even 30 donors pmp in 2 or 3 years. I don't see any substantial barriers that will prevent us from achieving this. We have all the necessary prerequisites ... We [NOD-Lb] just need a better budget and a little bit of rigor and continuity in the process. Nothing is impossible, we just need to convince the people in charge that this is a vital program"

-NOD-Lb participant-

#### 5.1.3.2. Identification

It is clear that NOD-Lb personnel define themselves through the success of their work. The unpredictable nature of the organ donation and transplantation process, requires a high degree of commitment from NOD-Lb as they have to be on call at all times of the day and night. Whenever, a potential donor is identified, the NC follows up on all eight steps of the process from the detection and referral to the end result be it a refusal or a transplantation. In fact, 60-70% of the time the NC is at the retrieval site in a supervisory capacity to make sure that the process runs well. Even when not there in person, the NC follows up by phone and is available in emergencies and when support or decision-making is required.

Other than the monthly salaries, there is no financial gain in the process. In fact, the budget allocated by the MoPH is more often than not insufficient and there is a need to supplement it through extensive fundraising and donations. Given the political instability and the economic deficit the budget has even gone missing a couple of times only to be reimbursed two to three years later. During that time NOD-Lb personnel have had to pay out of their own pockets to keep the program going. They derive personal satisfaction from the success of the program and in that sense, treat the organization as if it was their own personal property.

Another indication of the commitment of NOD-Lb is the case-by-case problem-solving process that is always managed under crises and in emergency situations. Punctual, spur of the moment solutions to deal with obstacles as they arise seems to be the norm

rather than the exception in the donation process. Most solutions are based on interpersonal relationships and the concerted efforts of the NOD-Lb team as is evident in the example described in the previous chapter in whereby undersupplied stock was flown in from neighboring countries.

#### 5.1.3.3. A legitimacy based on medical expertise

"In the MoPH there is no specialized entity that has the expertise to deal with organ donation issues".

-MoPH participant-

Although legitimized by a law and several ministerial decrees, NOD-Lb's main power comes from its expertise in the field and the lack thereof within the MoPH. The MoPH has delegated to NOD-Lb the responsibility of overseeing all activities related to organ donation and transplantation in Lebanon. By law, NOD-Lb has been designed as the regulator whose duties include coordination of both living and deceased donation processes, training of health professionals, sensitizing the public and building its awareness, following-up on deceased donation from start to end, decision-making as this entity has the necessary technical/medical expertise and on the ground implementation.

"the files start at NOD-LB, then go through the DG, to arrive to the MoH complete with suggested approval, awaiting ratification"

-NOD-Lb participant-

The MoPH enforces legislature, passes new laws and is supposed to allocate financial resources and provide continuous support and endorsement for all NOD-Lb activities.

"NOD-Lb and the scientific and ethical committees in the Lebanese order of physicians should have all the power. They [NOD-Lb] have the scientific and ethical responsibilities while the MoPH acts as a political/administrative body that legitimizes their work. To date, the MoPH has succeeded in shielding NOD-Lb and the process of organ donation from personal/financial interests and political influences. Ethical standards and recommendations are being strictly applied and observed."

-MoPH participant-

Added to that, the fact that NOD-Lb exhibits structural separation and managerial autonomy and lacks managerial accountability attest to its personal rather than institutional source of power and to the institutional distance and latitude in decision making that it enjoys.

#### 5.1.3.4. An intuitu personae source of trust?

The collaboration between the MoPH and NOD-Lb, which started ten years ago, continues today with no particular end in sight. It is a long-term association mostly informal in nature characterized by personal relationships and individual contacts. The modalities of the collaboration are neither institutionalized nor documented but consist of adhoc need-based meetings initiated by NOD-Lb.

"NOD-Lb collaborates directly with DG [...] There is no clear collaboration process [...] It is not written anywhere [...] There is no unit in the MoPH, there is NOD outside the MoPH".

#### -MoPH participant-

Given the personal nature of the relationship, it is clear that the collaboration is governed by mutual trust in and respect for both parties. From the government perspective, the mere existence of NOD-Lb in its present form and with its allocated responsibilities and privileges is a testimony to the MoPH's belief in NOD-Lb's competence, benevolence, and integrity. The lack of managerial accountability and control mechanisms reinforces the trust aspect of the collaboration.

In an environment based on dialogue, shared input and common decision-making, the interdependence of the MoPH and NOD-Lb is clear. Although the decisions are initiated by NOD-Lb, they have to be endorsed and amended by the MoPH in order to become effective. Therefore, NOD-Lb acts as a regulator and implementer while the MoPH is the legislator. All partners participate in meetings, discussions and activities and work towards building an efficient system for national organ donation and transplantation.

#### 5.1.3.5. Cultural differences

As described in chapter 4, the Lebanese culture definitely has its own specificities which have left their imprint on the process of organ donation and transplantation. At the forefront is the role of the personal network as a central element of Lebanese culture.

This was clearly a consideration for the establishment of the PPP in its present form.

NOD-Lb was entrusted to individuals with the proper expertise who were known in the field and more importantly were part of the organ donation and transplantation fabric prior to the creation of NOD-Lb. In fact, the main individuals tasked with setting up the system where specifically and personally chosen. Their involvement in organ donation and transplantation started well before the creation of NOD-Lb and they were instrumental in bringing about numerous changes. They were involved in the first center for kidney transplantation established in the country, were members of ALDOR, one of the first NGOs to work on organ donation and transplantation and had already closely collaborated in different capacities with the MoH and the President of the LOP at the time. Moreover, as will be apparent in the next chapter, the collaboration between NOD-Lb and the MoPH is strongly influenced by the relational and is based on interpersonal relations and mutual trust.

"the collaboration is on a personal, individual basis"
-NOD-Lb participant-

"collaboration is important and necessary but needs to be formalized, it cannot stay based on personal relations [...]. If the current medical director and regional coordinator leave, I am not sure what will happen to the program. It depends on those who come after. The personal influence is important".

-MoPH participant-

The collectivism found in the Lebanese society is also apparent in the regulation of organ donation and transplantation. NOD-Lb is concerned with the public good and "saving sick people". It works towards the common goal of saving lives in a timely and cost-efficient manner. The mission of NOD-Lb consists of increasing transplantation rates in the country by promoting deceased and living organ donation in an organized and ethical manner.

"guarantee safety, medical ethics and equity are respected in the donation of organs"
-NOD-Lb participant-

The power distance is also clear in the Lebanese society where globalization, immigration and open-border policies have brought about many social changes, but have failed to alter the tolerance towards power differences that are inherent to Lebanese society which still favors unity based on blood ties and kinship (Asmar, 2011). Place and clan of birth play an important part and have consequences on the development of unions and alliances. The family has a central role in and influence on the public, political as well as private life of the individual. It is considered a platform for personal development offering support, solidarity and fulfillment to the individual. At the same time, it can also be restrictive, over-protective and limiting to the development of personal responsibility. Relationships are subject to a very strict patriarchal structure and hierarchy and material wealth holds an important position in the societal structure (Chaoul, 2003). In addition, the separation of genders in social life and leadership by consensus rather than authority and coercion generates solidarity as well as the dual

practice of allegiance and protection (Asmar, 2011). In Lebanon, religion and political allegiance play an instrumental role in the public nominations and thus have an impact on the appointment of the DG and MoH. In the arrangement of collaboration between NOD-Lb and the MoPH the MoH, who has the final say in the decision-making remains a remote power who keep his distance from the collaboration efforts.

Collectivist tendencies and high-power distance (Davis et al., 1997) combined with the historical evolution of NOD-Lb, the Lebanese political traditions, policy development and implementation and political leadership are contextual factors that alter the process and outcomes of agencification (Badran, 2012; Thatcher, 2002). This is especially true in countries in transition where agencification usually implies the creation of new autonomous bodies for new functions (Nchukwe & Adejuwon, 2014; Sulle, 2010). Although agencification in these countries might not be a new concept, it is usually used to counter the corruption of state-owned companies and is rarely studied within a systematic conceptual framework. In general, it is driven by foreign advice in a bid for financial aid and is transplanted from other countries without regard to the availability of other elements necessary for the legal set-up especially in terms of legal accountability and financial frameworks. As a result, the latter are irregular, often presented on a caseby case basis to provide a quick solution to unexpected results and negative consequences. Davis et al (1997) suggest that in such cases of instability an involvement-oriented steward solution might be more efficient than a control-oriented agency solution.

#### 5.1.4. NOD-Lb more of a steward?

This chapter presents an attempt to reconcile the economic and psychosocial approaches to governance in an effort to define the characteristics of the independent regulatory agency in charge of the organ donation and transplantation process in Lebanon. The agency theory promotes an economic approach to governance that sees the regulator as individualistic, opportunistic and self-serving whereas the stewardship theory applies a psycho-social approach which depicts the regulator as collectivist proorganizational and trustworthy (Davis et al., 1997). This chapter contends that to understand the regulatory role of NOD-LB in organ donation and transplantation in Lebanon, it is necessary to mix and match components of both theories to present a new profile of a regulatory agency. From the agency theory, NOD-Lb borrowed the elements of structural separation, managerial autonomy and high-power distance. However, it did not display managerial accountability and evolved in a society with collective tendencies. Moreover, its higher order needs, intrinsic motivation, high value commitment, personal power due to expertise, the trust involved in the long-term commitment to governance efforts position NOD-Lb more towards the stewardship continuum. This could also explain the frustration and sense of betrayal experienced by NOD-Lb when the MoPH, who is mostly agreeable, suddenly switches gears and acts opportunistically. It is also interesting to note that although opportunistic behavior can go both ways, this theory does not account for problems with the principal, only with the agent. However, when the principal is a public sector official, the risk in some contexts might actually go both ways.

Therefore, in the case of the PPP for the governance of organ donation and transplantation in Lebanon, it would appear that the regulator, NOD-Lb, acts more as a steward than an agent. Practically this would suggest that NOD-Lb has less opportunistic and more altruistic tendencies and given their concern with the common good rather than individual advancement would require lower levels of management control.

The next section further analyzes the PPP itself in order to between the MoPH and the private entity NOD-Lb. The section highlights the fragmented context and legislature that led to the development of a partnership based on mutuality, organizational identity and trust but lacked commitment and stability.

# 5.2. A REFINED ANALYTICAL GRID FOR PPP-BASED GOVERNANCE OF ORGAN DONATION AND TRANSPLANTATION

#### 5.2.1. A theoretical framework for PPPs

Governments nowadays collaborate with private partners in the provision of public services that they either do not want to or cannot undertake primarily because they do not have the required expertise (Salamon, 2001; Simonet, 2008). In the provision of health care as in other fields, this collaboration between the state and the private sector has proved to be more successful in some areas and contexts than others (Simonet, 2008; Zaidi et al., 2012).

A collaboration requires the involvement of two or more entities in a reciprocal evolving process that entails joint participation in activities aimed towards achieving a common goal (Bedwell et al., 2012). Different forms of collaboration between the government and the private sector have been identified and endorsed by proponents of various philosophies. Instead of the government being the sole reference for problem-solving, tenants of the NPM philosophy have argued for the need for alternative service delivery mechanisms such as contracting out, privatization or public private partnerships (Ohemeng & Grant, 2014; Salamon, 2001). Dissatisfaction with both the public delivery mode and the private one led supporters of the New Public Service movement to propose a mixed delivery model that would ensure that the government's involvement in the service delivery process would continue beyond the authorization of the contract (Warner & Hefetz, 2008). Similarly, advocates of New Public Governance are calling for collaborative governance whereby private participation exceeds the role of the enforcer to engage in a more shared effort (Ansell & Gash, 2007; Jing & Hu, 2017). Regardless of the theory, the engagement of both governments and nonprofits in any mode of collaboration is governed by a multiplicity of contextual factors (Simonet, 2008) including the wider policy and political context (Zaidi et al., 2012), the historical and institutional context, the structure of the government in terms of decentralization and source of political power, leadership characteristics of various actors, the nature of the relationship between the collaborating parties (Mcloughlin, 2011) as well as a favorable legal environment and governmental financial support (Kabdiyeva & Dixon, 2014).

Reforms inspired by NPM doctrines have argued for the need for alternative service delivery mechanisms such as contracting out, privatization or public private partnerships whereby the government ceases to be the sole reference for problem-solving (Ohemeng & Grant, 2014; Salamon, 2001). For example, the British Private Finance Initiative (PFI), an initiative issued in the 90's, was promoted as a means to favor public investment in a restricted resource context (Barlow & Köberle-Gaiser, 2008). This enabled public bodies like local governments, to upgrade their infrastructure and introduce new patient safety standards by engaging private companies from both the bank/insurance and building sectors to fund public hospitals and other public equipment. Building on such initiatives, the provision of health care has seen the rise of other forms of PPPs that can be observed articulating public policy implementation with associations, foundations, or agencies operating in a more flexible way than public entities (Gazley, 2008). As in other fields, this collaboration between the state and the private sector has proved to be more successful in some areas and contexts than others (Simonet, 2008; Zaidi et al., 2012).

Organ donation and transplantation is one particular area in the health care sector where countries have proposed different forms of collaborations between the state and the private sector in order to fulfill the World Health Organization directive for countries to achieve self-sufficiency with respect to the organ donation and transplantation requirements of their citizens (WHO et al., 2011).

Asquith et al. (2015) adapted from Erridge and Nondi (1994) a framework for describing PPPs based upon a mix of the models of partnership and competition and focuses primarily on the concepts of relationships, trust, stability, and commitment.

Relationships based on interorganizational collaboration have received considerable attention in the last few decades (J. M. Brinkerhoff, 2002; Huxham, 2003; Irfan et al., 2017). Several theoretical frameworks, that capitalize on different underlying theories, focus on various major components and emphasize different aspect of the collaboration between the state and the private sector, have been proposed (J. M. Brinkerhoff & Brinkerhoff, 2002; Bryson et al., 2015). This collaboration has been addressed within a multitude of disciplines from various sectors using different theoretical approaches and research methodologies (Bedwell et al., 2012; D. W. Brinkerhoff & Brinkerhoff, 2011; Huxham, 2003). As a result, differences in terminologies and interpretations have led to considerable overlap among the various disciplines and some confusion and difficulty in reconciling information coming from the various perspectives. For example, differences or similarities between the terms 'partnership', 'alliance', 'collaboration', 'network', 'interorganizational relations', are yet to be established and properly designated (Huxham, 2003). Regardless of the field or terminology, the theory of collaborative advantage stipulates that collaboration occurs when it leads to outcomes or outputs that could not have been achieved through the individual actions of any of the collaborating organizations. Along the same lines, Brinkerhoff & Brinkerhoff suggest that a partnership "implies a cross-sectoral relationship where the actors involved bring both commitment and competence to the table, thereby creating the classic synergy (the

whole being more than the sum of the parts)" (D. W. Brinkerhoff & Brinkerhoff, 2011, p.3).

J. M. Brinkerhoff (2002) defines partnership as a "dynamic relationship among diverse actors, based on mutually agreed upon objectives, pursued through a shared understanding of the most rational division of labor based on the respective comparative advantages of each partner." (J. M. Brinkerhoff, 2002, p.21). Using this definition, J. M. Brinkerhoff (2002) proposes a partnership model that analyses the process of the collaboration itself (D. W. Brinkerhoff & Brinkerhoff, 2011). Rather than identify what a partnership is or focus on external influential factors (inputs) or the efficiency (outputs) of the collaboration, the model depicts partnership as a relative phenomenon defined by the extent of the partnership characteristics (figure 5.2). Based on the interaction of organizational identity and mutuality the model suggests four possible states of collaboration between governments and non-profits namely partnership, contracting, extension as well as co-optation and gradual absorption (J. M. Brinkerhoff, 2002; Irfan et al., 2017).

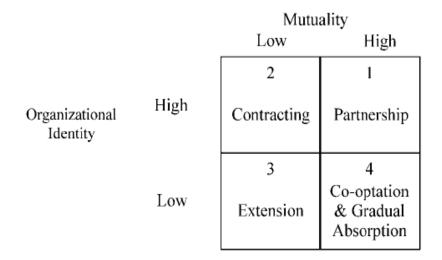


Figure 5.2: Partnership model

Source: J. M. Brinkerhoff, 2002

Mutuality defines the mutual dependence or interdependence of the collaborating organizations whereby each is aware of its rights and responsibilities and seeks to maximize the benefits to be gained from the partnership (J. M. Brinkerhoff, 2002). This includes a mutual commitment to the goals and objectives of the collaboration, supportive behavior and process integration with more frequent formal and adhoc interaction, communication and decision-making. It is a horizontal process characterized by a certain equality in decision-making whereby all the concerned organizations have some input into the shared objectives, processes, outcomes and evaluation.

Organization identity pinpoints the reason for selecting particular partners for collaboration and encompasses the particular competences and capabilities that each organization contributes to the partnership as well as the organization's capacity to

remain faithful and committed to its own mission and values (J. M. Brinkerhoff, 2002). Organizations involved in a partnership need to preserve their comparative advantage by consistently maintaining what is distinctive and important about them or in other words their contribution to the partnership. This contribution can come in any form namely financial, material, expertise, information, contacts, legitimacy and credibility.

Mutual trust in a PPP context, will be analyzed based on the three dimensions of trustworthiness, namely: competence (expertise and level of skill), benevolence (actions are not contingent on personal benefit), and integrity (shared value systems as well as work and ethical standards) (McKnight et al., 2002; Padma et al., 2017).

## 5.2.2. The Lebanese PPP for the governance of organ donation and transplantation

5.2.2.1. The context and nature of the partnership contract

At the time of the inception of NOD-Lb, there was no entity within the organization chart of the MoPH capable of undertaking its mission. Therefore, it was difficult to create a public agency with the required competencies to regulate and coordinate the process of organ donation and transplantation. This resulted in the delegation of the task to a committee of concerned professionals that eventually, given the complexity of the commission, became an organization with a regulatory framework, a budget, an authority conferred to it by the MoPH and a legitimacy afforded to it by public funding.

A series of Lebanese laws and decrees, already reviewed in previous chapters, have led to the establishment of NOD-Lb in its present state and function. Other than these

laws, there is no binding contract that describes the expectations, inputs and outputs of the collaboration between this organization and the state. Therefore, the only official document that exists is the decree creating NOD-Lb and subsequent decrees or regulations detailing its structure and allocating its responsibilities. All formal documents merely specify a series of tasks with no specific deliverables or time frames. In addition, there are no accountability mechanisms.

#### 5.2.2.2. The characteristics of the partnership

There are two major stakeholders involved in the governance of organ donation and transplantation in Lebanon namely, the MoPH and NOD-Lb. Officially, it is the current MoH and the DG of the MoPH who are in charge of organ donation, procurement and transplantation. They have the legal power and authority to make and enforce all laws concerning organ donation and transplantation in Lebanon. However, since the MoPH, who is more of an administrative than a medical entity, lacks the medical expertise in this domain, the responsibility for decision-making about deceased organ donation and transplantation has been attributed, by law, to NOD-Lb.

"In the MoPH there is no specialized entity that has the expertise to deal with organ donation issues"

-MoPH participant-

Therefore, in practice, it is NOD-Lb who provides the actual expertise, makes the decisions, suggests the laws, rules and regulations, implements them on the ground

and supervises all organ and tissue donation and transplantation in Lebanon. Decisions are usually taken by the Vice President of the Board, who is also the Medical Director of NOD-Lb, after consultation with the NC and the regional coordinators for organ donation and transplantation. Once ready, they are submission to the board for final approval. They are then presented to the DG of the MoPH for approval and once approved, are countersigned by the MoH to become officially effective.

"the files start at NOD-Lb, then go through the DG, to arrive to the MoH complete with suggested approval, awaiting ratification"

-NOD-Lb participant-

The MoPH has delegated to NOD-Lb the responsibility of overseeing all activities related to organ donation and transplantation in Lebanon. By law, NOD-Lb has been designed as the regulator whose duties include coordination of both living and deceased donation processes, training of health professionals, sensitization and building the awareness of the public, following-up on deceased donation from start to end, decision-making as this entity has the necessary technical/medical expertise and on the ground implementation. The MoPH enforces legislature, passes new laws, allocates financial resources and provides continuous support and endorsement for all NOD-Lb activities.

"NOD-Lb and the scientific and ethical committees in the Lebanese order of physicians should have all the power. They [NOD-Lb] have the scientific and ethical responsibilities while the MoPH acts as a political/administrative body that legitimizes their work. To date, the MoPH has succeeded in shielding NOD-Lb and the process of organ donation from personal/financial interests and political influences. Ethical standards and recommendations are being strictly applied and observed."

-MoPH participant-

The primary characteristics of the PPP will be presented as illustrated in the adapted framework of Asquith et al (2015). These include relationships, trust, stability and commitment as seen in the process of organ donation and transplantation in Lebanon.

5.2.2.2.1. Relationships: a partnership based on mutuality and organizational identity Although sanctioned by a decree and legitimized by law, the collaboration between the MoPH and NOD-Lb, is informal characterized by personal relationships and contacts. The modalities of the collaboration are neither institutionalized nor documented but consist of adhoc need-based meetings initiated by NOD-Lb.

"NOD-Lb collaborates directly with DG... There is no clear collaboration process... It is not written anywhere... There is no unit in the MoPH, there is NOD outside the MoPH"

-MoPH participant-

Since there is no specialized unit within the MoPH that is in charge of organ donation and transplantation, most of the public private interaction occurs between the MD of NOD-Lb, the NC for organ donation and transplantation (also NOD-Lb), the DG of the MoPH. In punctual instances, NOD-Lb collaborates with a few heads of departments in the MoPH, especially when dealing with technical issues. For example, in order to incorporate organ donation and transplantation within the accreditation rules for hospitals the NC had to work closely with the Director of Technology.

"The NC comes and works directly with the DG"
-MoPH participant-

"The collaboration with NOD-Lb occurs at the level of the DG. It should actually start at a lower level but since a specialized department is not available and the subject is important it comes directly to the DG"

-MoPH participant-

This collaboration between the MoPH and NOD-Lb is exemplified by the definition put forward by Bedwell et al. (2012) which suggests that a collaboration requires the involvement of two or more entities in a reciprocal evolving process that entails joint participation in activities aimed towards achieving a common goal. Using J.M Brinkerhoff's partnership model (2002), the relationship between MoPH and NOD-Lb can be described as a partnership with relatively high organizational identify and mutuality.

In terms of organization identity all organizations are driven by their institutional interests and priorities (J. M. Brinkerhoff, 2002; Najam, 2000). It is evident in this case that both collaborating organizations have clear missions and goals that have not deviated since the beginning of the partnership. They each have well-defined and strongly delineated roles that enable them to strive to fulfill their shared goals and mission. The strength of NOD-Lb remains in its medical and technical expertise, while the government maintains its legislative support. There appears to be no particular threat to each organization's identity within the partnership. Similarly, there have been no apparent changes in or compromises of their visions. Although the roles are attributed by law, they have jointly worked on amending it in order to improve their collaboration and maintain their complementarity.

In an environment based on dialogue, shared input and common decision-making, the mutual dependence (Thomson et al., 2007) of the MoPH and NOD-Lb is clear. Although the decisions are initiated by NOD-Lb, they have to be endorsed and amended by the MoPH in order to become effective. They have both maintained their collaborative advantage (Huxham, 2003) with NOD-Lb acting as a regulator and implementer and the MoPH as the legislator. All partners participate in meetings, discussions and activities and work towards building an efficient system for national organ donation and transplantation. A similar definition of mutuality is put forth by Mayo-Gamble et al (2017) whereby mutuality is described as "a shared interest in building and enhancing a formal

infrastructure within respective organizations that fosters continual cooperation and collaboration to achieve mutual benefit" (Mayo-Gamble et al., 2017, p.604).

The relationship appears to have all the characteristics of a partnership except for the need for a more formalized and structured process. Given that the literature on partnership has shown that not all indicators of mutuality are necessary in the definition of a partnership (Irfan et al., 2017), the collaboration between the MoPH and NOD-Lb could easily be positioned as a partnership, despite the lack of a structured process. The added value of the partnership lies in its provision of a much-needed platform to achieve self-sufficiency with respect to the organ donation and transplantation requirements of the country; a feat which would not have been possible if each entity was working alone.

### 5.2.2.2.2. Trust: a basis for the PPP

Given the personal nature of the relationship it is clear that the collaboration is governed by mutual trust in and respect for both parties (Mcloughlin, 2011). From the perspective of NOD-Lb their dedication and perseverance in a climate of administrative, political and financial adversity bears witness to their belief in the process, the system and more importantly the fruits of the collaboration. The following statements by NOD-Lb attest to this fact.

"We [NOD-Lb] need rules and regulations and only the MoPH can make the law"

"if NOD-Lb stops the file, the MoPH will stop the process"

"...with respect to the laws to get the program working, the MoPH is providing good support"

### -NOD-Lb participant-

From the government perspective, the mere existence of NOD-Lb in its present form and with its allocated responsibilities and privileges is a testimony to the MoPH's belief in NOD-Lb's competence, benevolence, and integrity.

Established to consolidate organ donation and transplantation efforts into one organization sanctioned by legislature, NOD-Lb provides the expertise necessary to regulate an extremely specialized unit. The ministerial decree (1/65) that drove the conception and delimited the role and responsibilities of NOD-Lb provides institutional distance as the regulator is given the sole responsibility of supervising and coordinating all organ donation and transplantation activities pertaining to both deceased and live donation. As per the decree, the organization has its own governing board that is headed by a president. The organization has a separate budget allocated by the MoPH and serves as the Lebanese "face" of organ donation and transplantation both locally and abroad. In fact, its role spans a wide array of responsibilities and functions that enable the organization to benefit from a considerable level of autonomy and flexibility in decision-making concerning human and financial resources as well as operational management. There are no external monitoring mechanisms or evaluation routines and no incentives or controls in the form of rewards or sanctions on NOD-Lb from the part of the MoPH. A main reason for this could be that NOD-Lb's motivation appears to be

altruistic rather than opportunistic and is driven by a strong belief in the process and the need for a national system for organ donation and transplantation.

### 5.2.2.3. Commitment: a notion without conviction

The main objective "increasing the organ donation rate to 20 donors / Million Inhabitants by 2020", vision "to save and enhance the lives of as many people as possible in Lebanon through organ and tissue donation and transplantation" and mission "increasing the organ and tissue donation rate to reach self-sufficiency through implementing a Lebanese model for organ and tissue donation and transplantation" of NOD-Lb (NOD-LB /, n.d.) are a clear statement of its commitment to the process. This is especially true as NOD-Lb is aware of the importance of the support of the MoPH as it attempts to implement and enforce the laws and legislature and regulate the program.

"...you cannot enter a hospital and check medical records except if you are affiliated to the MoPH. Collaboration provides the official title that you are affiliated with the government, with the MoPH, ... to enable you to enter hospitals, to be able to go and see, to oversee what is happening in the hospitals, to be able to ask from the doctors...

They cannot forbid you entering and seeing everything"

-NOD-Lb participant-

In theory, the MoPH also appears to be committed to the process and believes that "organ donation is important technically, financially and ethically". As such it strives to reinforce the program by endorsing most of the decisions proposed by NOD-Lb and strives to facilitate the implementation of the process.

"if NOD-Lb stops the file, the MoPH will stop the process"
-NOD-Lb participant-

In practice, however, the commitment is slow to come as the MoPH does its duty but does not go the extra mile. Moreover, the economic situation, bureaucratic red tape and political agendas take its toll on the contribution of the MoPH to the program.

Due to the continuous support of both parties, the partnership between the MoPH and NOD-Lb has had several success stories. Laws have been progressively amended and improved including the law concerning the imports of human tissues and that concerning the allocation criteria of organs. A national registry for organ donation and transplantation has been established, organ donation cards are accruing daily, and the plan was to eventually include the program for organ donation and transplantation within the National Health plan. NOD-Lb oversees all media interventions related to organ donation and transplantation and has been provided with the necessary legitimacy to ensure quality control by conducting audits and checking hospital records. In addition, to ensure the cooperation of hospitals, standards for organ donation and transplantation have been incorporated in the hospital accreditation standards.

"If you take into consideration the financial, political and administrative situation in the country, I believe that the results are very good"

-MoPH participant-

The program of organ donation and transplantation is essential and has a promising future if properly managed and supplied with appropriate human and material resources. There are a lot of sick people who depend on this program and it needs to be prioritized. However, the commitment on the governmental side is not always as clearly formulated.

"if they provide it with human and material resources the program has an important future as there a lot of patients their lives are contingent on the application of this program, you will have to help a lot of people with this program. It needs to be prioritized."

### -MoPH participant-

The Lebanese organ donation and transplantation program has considerable potential if the law is amended to define the responsibilities of all stakeholders, the collaboration process and the duties of all the Ministries involved (health, media, law, education and interior) with the MoPH as a focal point to all government collaboration. There is no reason why the program should not reach the same levels as other successful countries; the infrastructure exists; all that is needed is stronger legislature and financing.

"I don't see the reason why small countries in Europe have managed to achieve 30 deceased donors pmp and we [Lebanon]can't achieve 20, 25 even 30 donors pmp in 2 or 3 years. I don't see any substantial barriers that will prevent us from achieving this. We have all the necessary prerequisites ... We [NOD-Lb] just need a better budget and

a little bit of rigor and continuity in the process. Nothing is impossible, we just need to convince the people in charge that this is a vital program."

-NOD-Lb participant-

### 5.2.2.4. Stability: a missing component

Although the collaboration with the DG is described as stable and positive, it remains personal in nature and lacks formalization. The adhoc aspect of the relations between the two entities and the lack of a defined, documented process with a key contact person or entity within the MoPH leads to breaks in the continuity and stability of the program.

"there should be meetings between the two parties, not only when we need something we ask for a meeting, maybe we get it and maybe we don't, ... we need someone in the MoPH as a reference for us... meetings with regional coordinators four times a year."

-NOD-Lb participant-

"collaboration is important and necessary but needs to be formalized, it cannot stay based on personal relations ... If the current medical director and regional coordinator leave, I am not sure what will happen to the program. It depends on those who come after. The personal influence is important."

-MoPH- participant

"Having an expert within the MoPH to follow up on the process would make things easier and faster. In principle it is a good idea if it were possible."

-MoPH participant-

In such a situation, the personal agenda and aspirations of individuals new to the equation, could easily disrupt a process that has no formal structure and suffers from administrative routines and time lags.

"the MoPH takes time, all administrative issues take time to get processed from one person to the next and for the MoH to approve it could take half a year, 2 years sometimes to decide on something and in the meantime the other parties are starting a process with no guidelines or legal legitimacy."

-NOD-Lb participant-

Closely associated to the informal nature of the collaboration is the lack of continuity in the process that changes with every change in the ministry.

"The MoH change, they come and they go. Every time a new MoH comes, there is no continuity in our country, the problem in the ministries is that there is no continuity. A MoH comes, a MOH goes, he brings with him his own group to work with him. In order to enlighten this group about organ donation as there is no one who knows the ins and outs of the process in all its minute details takes us around a year. It is possible that this particular ministry will go in a year and 2 months or 6 months. So we would have lost a year as easily as that. That is the problem with the endorsement that is not constant."

-NOD-Lb participant-

In addition, the partnership with the MoPH is contingent on the current MoH and his desire for or policy of involvement. As the MoH changes, the collaboration gets restructured by introducing and accommodating new individuals, stipulations and/or committees. Since the MoH usually does not have the required expertise, the changes are not always beneficial to the process which has to restart with every new MoH unless he chooses to rely on the DG who provides the required stability and constancy to the process and is a knowledgeable and capable facilitator.

"It depends on each MoH that comes and his vision. That is if the MoH comes with a vision that NOD-Lb should be in charge of everything and work with the DG, we do what needs to be done and the program takes off and we work very well. Another MoH comes and his vision is that we should be slightly more lenient so he removes a committee and replaces it by a committee whose members are not knowledgeable about the subject and we have to work to get people back on track."

-NOD-Lb participant-

Added to that, although the DG of the MoPH has been a constant figure in the struggle to establish organ donation and transplantation in the country the MoH who has the final say has been the uncertain link in the chain. There are no guarantees with the MoH who can here one day and gone the next as ministries form and resign with ease in the current political context which has a tendency to be capricious to say the least. Not only that but the MoH always comes with a political agenda and personal allegiances. Given that organ donation and transplantation has not yet been established as part of the

National Health Plan it could just as easily be forgotten or overlooked for a term.

Budgets, organizational structures, board members although part of the ministerial decree are in effect all subject to the MoH's whims and plans for his term in office.

Other external factors hinder the outputs of the collaboration rather than the process itself. These include the political situation of the country, the governmental and policy restrictions placed on the current MoH and the financial constraints and inadequate budget provided for the program.

"They have things that are positive that enable collaboration but then politics get involved and it messes thing up."

-NOD-Lb participant-

### 5.2.3. The governance of organ donation and transplantation: A PPP built on trust

The PPP established between the MoPH and NOD-Lb for the governance of organ donation and transplantation is based on a relationship characterized by organizational identity and mutuality. There is strong evidence of trust between both parties as well as mutual respect and a tentative commitment to support the program. The only aspect of a true partnership that is missing is the institutionalization of the relationship which appears to be more of an informed decision that was impulsively established and continues to be run in an adhoc manner. In terms of the PPP characteristics, although there are several success stories and there is a general satisfaction with the

collaboration, its performance is hindered by a lack of complete commitment on the part of the state and an instability that is reflective of the politics and general situation in the region and more particularly the country.

The process of organ donation and transplantation in Lebanon is an example of a public private partnership established between the Lebanese Ministry of Public Health and a private entity namely, NOD-Lb, which was specifically created to manage and regulate the process based on the expertise of its members. The organization was legitimized through a decree that clearly delineated the role of the organization, the participants, their titles and duties. What remains undefined however, are the expected outputs of the process and the type of control mechanisms that the state would enforce to regulate the partnership itself. The next section will discuss these issues by revisiting performance management and interorganizational control literature in order to address the problems of governance of organ donation and transplantation formerly analyzed.

As an independent regulatory agency, NOD-Lb combines elements from both agency and stewardship with a stronger pull towards the latter. NOD-Lb is characterized by structural separation, managerial autonomy but not managerial accountability. The latter becomes redundant when combined with higher order needs, intrinsic motivation, high value commitment and personal power due to expertise. This engenders trust and long-term commitment which might minimize the urgency for strict accountability mechanisms that are usually part and parcel of traditional PPP arrangements. OPOs in the USA are subjected to licensing and certification by an external body. Even in France, the ABM, which is a public agency, signs, with the Ministry of Health, a

performance contract that details the expected objectives to be met by the ABM over a specified period of time. In Lebanon, according to a respondent from the MoPH, this is not deemed necessary as NOD-Lb does not take any bilateral decisions. Another explanation lies in the duality of the Lebanese context which is characterized by collectivism on one hand and high-power distance on the other.

Using J. M. Brinkerhoff's Partnership Model (2002), the collaboration between the MoPH and NOD-Lb can be described as a partnership with organizational identity and mutuality that is based on trust and personal relations and is only missing institutionalization. In fact, the collaboration remains adhoc with meetings scheduled on a need-based basis. It appears as if the collaboration is in fact driven by a laissez-faire attitude whereby the MoPH only gets involved if there is a need for a new law to be ratified or a new budget to be discussed. Otherwise, NOD-Lb is pretty much left to its own devices. In essence, the process is governed and implemented by the regulator with the MoPH's stamp of approval. Given that the regulator is more of the expert in this matter this would make sense except that the regulator lacks the authority and power to enforce the rules. This leads to a situation whereby the regulator needs to exert more control and as a result ends up doing everything.

li is clear that the process of organ donation and transplantation in Lebanon is an example of a public private partnership established between the Lebanese Ministry of Public Health and a private entity namely, NOD-Lb, which was specifically created to manage and regulate the process based on the expertise of its members. The

organization was legitimized through a decree that clearly delineated the role of the organization, the participants, their titles and duties. What remains undefined however, are the expected outputs of the process and the type of control mechanisms that the state would enforce to regulate the partnership itself. The next chapter will discuss these issues by revisiting performance management and interorganizational control literature.

# CHAPTER 6: PPP-BASED GOVERNANCE ISSUES REVISITED IN THE LIGHT OF INTERORGANIZATIONAL CONTROL

Revisiting the empirical and interpretative work in the previous chapters and putting them into perspective, suggests that the analysis of this public private partnership should be complemented by addressing a particular dimension of performance management namely, the issue of management controls and the determinants of the choice of control mechanisms. This warrants reconsidering the case in light of both the contracting out & interorganizational control literature and analyzing the case from the perspectives of accounting, economics and social theories. This in turn entails a closer look at the inter firm control mechanisms that govern the partnership between the two organizations and more importantly the factors that led to their institution. Therefore, similar to other work combining performance management and healthcare in the public sector (Georgescu, 2013), this chapter will borrow from the concepts of interorganizational controls to further explore and understand the challenges with organizational control in the Lebanese organ donation and transplantation system.

In an attempt to increase cost effectiveness and efficiency and promote better utilization of resources and expertise, outsourcing of public services to the private sector has extended to encompass the outsourcing of essential components such as management and maintenance (Narayanan et al., 2007; van der Meer-Kooistra & Vosselman, 2000). However, given that the objective behind the provision of public goods is improving the conditions of society as a whole rather than increasing personal or corporate wealth, accountability becomes a key issue in outsourcing in the public sector as a lack of

accountability can engender opportunistic behavior and lead to corruption which is essentially counter to the proposed objective of public service provision (Narayanan et al., 2007). Interfirm control mechanisms are therefore an essential component of public service outsourcing and the essence is to find a balance between accountability and transparency which require tighter controls and better service provision which is usually contingent on looser controls especially in situations where not all aspects of the partnership can be foreseen a priori and included in the contract. This in turn necessitates close collaboration and an intricate setup at both the macro (legal and institutional frameworks) and micro (internal/external coordination and cooperation) levels in order to allow the creation of appropriate interfirm control systems and processes (van der Meer-Kooistra & Vosselman, 2000).

Scholars have provided various definitions for interfirm control mechanisms but in essence they all agree that it consists of a set of mechanisms that influence behavior in order to achieve determined objectives (Speklé, 2001). Therefore, interfirm control is primarily concerned with behavior, goals and effectiveness and seeks to understand and explain factors that drive organizations to use different methods of control ranging from well-defined rules, procedures and standards to individual judgement as a guide to behavior.

Both contingency and agency theory have been used in an attempt to further the discussion on interfirm control and they have both succeeded in providing additional insight into the situation. However, contingency theory with its attempt to explain

interfirm control mechanisms based on a heterogeneous set of circumstantial factors and agency theory with its focus on specific aspects of the interfirm control mechanisms in "single period, single agent models" (Speklé, 2001, p.420), appear too constrained to capture control in its entirety.

## 6.1. TRANSACTION COST ECONOMICS: CONTRACTING PROBLEMS AND SOLUTIONS

Most of the literature on the governance of interorganizational collaboration has focused on transaction cost economics (TCE) originally developed by Williamson (Williamson, 2010) with the aim of explaining why some institutional arrangements work better in some circumstances than others (Greenberg et al., 2008; Langfield-Smith, 2008; Speklé, 2001). TCE thus, provides a framework that is commonly used to study the choice of governance structure and interfirm control mechanisms in outsourcing relations. According to the TCE model, an organization's economic activity is determined by the characteristics of transactions which lead to problems that are handled based on the context in which they arise.

The nature and magnitude of contracting problems can be explained by three characteristics of the transaction namely, the degree of asset specificity or idiosyncrasy of the transaction, its uncertainty or complexity and its frequency (Greenberg et al., 2008; Speklé, 2001; van der Meer-Kooistra & Vosselman, 2000). Asset specificity refers to the degree with which an asset is specifically tailored for a particular transaction or can easily be redeployed or transferred to a purpose other than the one for which it was

originally intended (Greenberg et al., 2008; Langfield-Smith, 2008; Speklé, 2001). It can be measured in terms of location, physical characteristics and human capital and reflects the value of the asset within the collaboration relative to outside it (Greenberg et al., 2008; Steenkamp & Geyskens, 2012) as well the losses incurred upon prematurely terminating the relationship and transferring the asset for alternative uses (Speklé, 2001). Higher asset specificity implies more interdependence which decreases market competition and increases the potential for opportunistic exploitation.

Transaction complexity or programmability refers to the degree with which the processes and outputs of the transaction can be predicted a priori (Greenberg et al., 2008; Speklé, 2001; van der Meer-Kooistra & Vosselman, 2000). Task uncertainty and complexity or unfamiliarity can make it difficult to clearly plan activities and define outputs ex ante which implies the need for a certain flexibility or incompleteness in the contract specifications that allow for adaptation as more information becomes available (Speklé, 2001). In such situations, control becomes delineated in terms of commitment and expectations rather than based on norms and standards.

Finally, frequency reflects the number of times an activity will need to be repeated (Greenberg et al., 2008; van der Meer-Kooistra & Vosselman, 2000). Its main contribution is in intensifying the problems and emphasizing the urgency in finding appropriate solutions (Speklé, 2001). Moreover, higher frequency may instigate higher costs which could also have an impact on the solution proposed (Langfield-Smith, 2008).

Exploring these characteristics in the case of NOD-Lb, suggests a high degree of asset specificity since the organization was essentially created for the purpose of regulating the organ donation and transplantation process and its redeployment or replacement would come at a considerable cost. Moreover, although familiar with the required tasks and their complexity, the outputs of the transaction are highly unpredictable and cannot be forecast a priori. It is therefore, despite the available level of skill and expertise, difficult to clearly plan activities and define specific outputs. Finally, in terms of frequency the exact number of times this would be needed is uncertain but it is definitely not intended to be a daily occurrence.

In terms of solutions, organization is a primordial ingredient in the coping mechanisms supported under this theory which mainly consist of aligning the appropriate governance mechanisms in terms of cost and competence with the specific transaction attributes (Speklé, 2001). In other words, all thing being equal, the governance structure that is associated with the lowest transaction cost will usually be the governance mode of choice (Dekker, 2004).

Three modes of governance namely, market, hybrid and hierarchy are recognized by TCE theory (Ditillo et al., 2015; Greenberg et al., 2008; Langfield-Smith, 2008; Speklé, 2001; van der Meer-Kooistra & Vosselman, 2000). Market and hierarchical governance are found on both ends of the governance continuum with market assuming readily available information, competing parties and homogeneous products while hierarchies consist of more bureaucratic systems with vertically integrated organizations. Hybrids include the whole array of governance mechanisms found in between the two

continuums. The theory provides guidance on the governance form that is best suited to a particular collaborative relationship. Therefore, in market governance, control is achieved through free competition whereas hierarchical governance depends on authority, internal incentive structures and monitoring (Speklé, 2001). Hybrid governance, on the other hand, assumes long term contracts and additional safety measures that promote compliance.

With these definitions in mind it would seem that the governance of organ donation and transplantation in Lebanon is closer to a hierarchy as it was established by law, hence authority, and based on an internal incentive structure with no contracts or competition.

### 6.2. THE THREE STAGES IN OUTSOURCING RELATIONS

Transaction cost theory which provides a basis for this work recognizes three phases in any outsourcing relation, namely contact, contract and execution with the potential for different control patterns and contingency factors at each stage (Narayanan et al., 2007; van der Meer-Kooistra & Vosselman, 2000). The contact stage encompasses the quest for an appropriate collaborator. It is the stage where potential candidates and organizations are reviewed and selected based on their reputation, technical skills and management capabilities. The contract phase focuses on the contract that will define the collaboration mechanism between both parties at the execution stage. This is the stage during which control and process structures are put in place and established with a view towards encouraging trustworthy behavior and commitment. It is at this stage

that various roles are defined and issues of authority, responsibility, gathering and supplying information, evaluation and payment are decided upon. Finally, the execution phase is the stage at which the plan is implemented, transactions are carried out and control activities are applied to ensure that the contract is respected and expected outputs are achieved. The object here is to achieve an atmosphere that enhances trust and promotes collaboration.

Applying this to the PPP between NOD-Lb and MoPH, the three stages can be characterized as follows. The contact stage was initiated in 2009 when the government stepped in with the instatement of ministerial decree 65 which served to define the board of NOD-Lb and the Lebanese system of organ donation and transplantation. Given that the MoPH was in a reform phase at the time, and their strategy leaned towards the enhancement of collaborative governance, consensus-oriented networks and consensual leadership in the management of processes for which they lacked the required expertise, the choice was to delegate the management of organ donation and transplantation to a private entity. However, rather than contracting out to an already existing body, through a bidding and selection process, the decision was made to create a new organization formed of specialists in the field who had a vested interest in promoting the issue of organ donation and transplantation and needed a platform within which to work. The members of the organization were specifically chosen based on their competence, reputation, already established role in organ donation and transplantation and previous collaboration with the MoPH and the MoH at the time. In 2012, NOD-Lb designated by the Code of Medical Ethics (No 240- art 30, 2012) as the only official

body responsible for supervising and coordinating all organ, tissue and cell donation and transplantation activities in Lebanon.

Practically, there appears to be no contract stage characterizing the collaboration

between NOD-Lb and the MoPH. The only official binding document that exists is the decree creating NOD-Lb and subsequent decrees or regulations detailing its structure and allocating its responsibilities. There is no contract with pre specified targets regulating the behavior of the decision-makers at NOD-Lb but rather all formal documents merely specify a series of tasks with no specific deliverables or time frames. In addition, there are no accountability mechanisms and no termination date. In fact, the only way the collaboration would end is through a ministerial decree changing the actors involved, their roles and the commitment of the MoPH to the process. In the same vein, all changes to the collaboration process are brought about through decrees. The execution stage of the outsourcing relation developed along the same lines as the contact/contract stage with the MoPH essentially allowing NOD-Lb free rein to explore options and propose solutions that it would then generally endorse if it could. NOD-Lb appears to be self-reliant and self-motivated continuously working towards the social goal of improving organ donation and transplantation rates and processes in Lebanon. Any goals set or achieved are self-imposed born out of a personal sense of commitment to the process and its success and a drive to achieve outputs similar to those of the more performant systems of organ donation and transplantation in the world. In fact, although NOD-Lb employs ex post controls in an attempt to control the hospitals that are part of the National Organ Procurement Network, the parent ministry has not

engaged in a similar effort in an attempt to control NOD-Lb. By reciprocity, the performance goals set by NOD-Lb serve to assess its own performance but there are no routinely scheduled external monitoring or evaluation mechanisms and no incentives or controls in the form of sanctions or rewards. The commitment of the MoPH to the process appears to be contingent on the political/financial situation in the country as well as the current MoH and his agenda and political affiliations. The relationship remains informal and personal based on competence and trust and the initial laws that have seen relatively no evolution or serious revisions with time.

### 6.3. TRANSACTION COST ECONOMICS AND TRUST

Interfirm control in outsourcing partnerships in the public sector requires an appropriate balance between formal and informal controls (Narayanan et al., 2007). As usual, the need for accountability and transparency in the public sector presupposes tight interfirm controls which offer visibility in the behavior of the outsourcing parties. However, given the incompleteness of the transaction due to information asymmetry and uncertain environments, there is also a need to rely on informal controls and trust. Building and sustaining trust at different levels and within all phases of the contract has been shown to be a key factor in the success of interorganizational relationships (Greenberg et al., 2008).

Incorporating both the economic and social perspectives, Van der Meer-Kooistra & Vosselman proposed in 2000 a model based on both transaction cost economics theory and trust based approaches (van der Meer-Kooistra & Vosselman, 2000). This model

for interfirm control mechanisms includes three control patterns namely market-based, bureaucracy based and trust based (table 5.1) and reorganizes the contingency factors into three categories: transaction, transaction environment and transaction party (table 5.2).

Table 6.1: Interfirm control patterns of collaborative relationships

	Market based pattern	Bureaucracy based pattern	Trust based pattern
Contact phase	Competitive bidding	Preselection of potential suppliers; bidding procedures; detailed selection criteria	Trust stemming from friendship, former contractual relationships or reputation
Contract phase	No detailed contracting; payment based on standardized activities or output	Detailed and comprehensive contracting; paument based on real activities or input	International contracting; framework contracts; contractual trust; loose links between payment and activities and output
Execution phase	Periodical, ex post conpetitive bidding	Supervision; performance measurement and evaluation; detailed ex post information processing; direct intervention	Personal consultation and coordination; development of competence trust and goodwill trust; process oriented and culture based control mechanisms

Source: van der Meer-Kooistra and Vosselman, 2000

Table 6.2: Characteristics of the contingency factors

Transaction	<b>Transaction Environment</b>	Transaction Parties
<ul> <li>Degree and type of asset specificity</li> <li>Frequency and reputation</li> <li>Length of transaction period</li> <li>Measurability of activities and output</li> </ul>	<ul> <li>Uncertainty about future contingencies</li> <li>Degree of market risk</li> <li>Institutional environment (rules, systems and organizations</li> </ul>	<ul> <li>Information asymmetry</li> <li>Reputation</li> <li>Experience with cooperation in networks or with specific parties</li> <li>Risk attitude</li> <li>Bargaining power</li> </ul>

Source: van der Meer-Kooistra and Vosselman, 2000

The characteristics of the transaction include degree and type of asset specificity, frequency and repeatability, length of the contract and measurability of the output as previously described. Moreover, van der Meer-Kooistra & Vosselman (2000) classify the uncertainty of the environment in a separate category under transaction characteristics and recognize the importance of the characteristics of the parties involved and their behaviors in the third and final factor (van der Meer-Kooistra & Vosselman, 2000).

The environmental characteristics develop from situations that could potentially influence the outcome of the collaboration but are not within the control of the collaborating agencies (Langfield-Smith, 2008). These encompass the uncertainty about future transactions, the potential market risks and the institutional environment with its rules systems and organizations (van der Meer-Kooistra & Vosselman, 2000). These characteristics could even extend to communication problems, cultural differences and even issues with political or legal systems (Greenberg et al., 2008).

The two main characteristics that determine the behavior of collaborating parties are bounded rationality and opportunism (Greenberg et al., 2008; Langfield-Smith, 2008; Speklé, 2001). Although the tendency of collaborating parties is to always act rationally, it is difficult to anticipate behaviors. As a result, since the contract or agreement between the parties cannot cover all contingencies this paves the way for potential opportunistic behavior. Behavioral characteristics include the collaborating parties' reputation and experience with networking, their risk sharing attitudes and the asymmetry in information and bargaining power between them (van der Meer-Kooistra & Vosselman, 2000).

Applying these concepts to the PPP between the MoPH and NOD-Lb and bearing in mind that the organization itself was created based on a need for the performance of a service that the MoPH was not equipped to handle due to lack of resources and expertise, it is not surprising that the control mechanism during the contact phase was based on trust patterns whereby the MoPH sought to establish an entity that consisted of individuals that had the required expertise and with whom it had previously successfully collaborated. In that instance the drivers behind the collaboration where mainly the representatives of the private sector 's reputations and the MoPH's trust in them which stemmed from previous collaborations and friendships. From all accounts, there was a combination of both goodwill and competence trust at this stage and interestingly enough it was evident in both the private sector as well as the MoPH. Given the context in which the PPP was first established trust played an important role in the structure of the PPP in terms of competence, good will and commitment. The

individuals who were chosen as officers of the organization had the necessary technical and management expertise, a proven track record in the field, were part of established institutions and had the appropriate certification and educational degrees. Added to that they were already invested in the field and committed to go beyond what was required to make the process successful. They had shared values and norms and did not require control or reciprocation to fulfil their obligations. This is also aligned with the essence of the Lebanese society where relational ties are more enhanced and reputation and personal acquaintances play an important role.

Trust-based control patterns remained dominant in the contract and execution stages. The ministerial decree that serves as a contract for the outsourcing relation presupposes contractual trust and provides loose links between payments and outputs since the payments come in the form of a predefined budget and the outputs are not pre specified. The only form of bureaucracy-based controls appears to be the need to present proof of expenditures in order to receive payments but that is more a function of it being the norm in public financing than a particular control mechanism of the PPP.

Also, although the fact that there was no detailed contracting might potentially reflect a characteristic of market-based controls but in this case it was more as a result of the existence of the law which was meant to replace the contract and increase the efficiency of the process. Similarly, in the execution phase, the presence of competence and goodwill trust and the impact of relational explanatory variables and the emphasis on personal consultation and coordination clearly highlights the continuing influence of

trust-based control mechanisms. A summary of the findings at each phase is presented in table 6.3.

Table 6.3: Interfirm control patterns for each stage in the public private partnership for the governance of organ donation and transplantation in Lebanon

Stages	Interfirm Control Patterns			
J	Market- based	Bureaucracy- based	Trust-based	
Contact stage			Trust stemming from friendship, former contractual relationships or reputation	
Contract stage	No detailed contracting	Payment based on real activities or output	Contractual trust, loose links between pay and activities and output	
Execution stage		·	Culture based control mechanism, competence trust, goodwill trust, personal consultation and coordination	

Source: Author's compilation (adapted from van der Meer-Kooistra & Vosselman, 2000)

### 6.3.1. Interfirm control mechanisms and contingency factors

The model proposed by van der Meer-Kooistra & Vosselman (2000) explains the choice of control mechanism as a function of the contingency factors at each stage of the partnership process (table 6.4). In essence, a separate assessment of the three proposed contingency factors at each stage of the collaboration process provides an understanding of the choice of interfirm control mechanisms used. Therefore, market-based patterns are based on short to medium term contracts that combine low asset specificity with high repetition and measurability of activities and output. In this form of control, social embeddedness and institutional factors do not play a major role as it is the market price that drives the collaboration. The availability of multiple interested and

competent parties accounts for low switching costs and makes the party characteristics irrelevant. The bureaucracy-based control mechanisms are best suited for medium to long term contracts that assume medium to high asset specificity, medium to low repetition and measurability of the outputs based on the contract. In this type of arrangement future contingencies are more or less known with medium to high market risks. Institutional factors play a role here in the extent that they impact of the rules set forth in the contract. Party characteristics include a reputation for competence, medium risk sharing attitude and asymmetry in bargaining power. Finally, trust-based control mechanisms work best for long term contracts with high specificity and low repetition and measurability. This mechanism is best suited to situations where future contingencies are unknown, market risks are high and social and institutional factors influence the relationship. Party characteristics include competence reputation, networking and contracting out experience, risk sharing attitude and no asymmetry in bargaining power.

Table 6.4: Contingency factors and interfirm control patterns

Contingency factors	Market based pattern	Bureaucracy based pattern	Trust based pattern
Transaction characteristics	Low asset specificity; high repetition; measurability of activities and output; short to medium term contract	Medium to high asset specificity which can be protected by contractual rules; low to medium repetition; measurability of activities and output based on contractual rules; short to medium term contracts	High asset specificity; low repetition; activities or output cannot be measured well; long term contract
Transaction environment characteristics	Many potential transaction parties; market price contains all the market information; social embeddedness and institutional factors are not important	Future contingencies are more or less known; medium to high market risks; institutional factors influence the market rules	Future contingencies are unknown; high market risks; social embeddedness; institutional factors influence the relationship
Party characteristics	Not important because there are many parties with the same characteristics due to which switching costs are low	Competence reputation; medium risk sharing attitude; asymmetry in bargaining power	Competence reputation; experience in networks; experience with contracting parties; risk sharing attitude; no asymmetry in bargaining power

Source: van der Meer-Kooistra and Vosselman, 2000

The control patterns described here are presented as a continuum on a spectrum with other researchers highlighting the possibility of combining different elements to create different archetypes within that spectrum (Caglio & Ditillo, 2008; Ditillo et al., 2015; Speklé, 2001). Table 6.5 shows how different levels of the transaction characteristics combine together to explain the resulting archetypes of control.

Table 6.5: Control archetypes and their determinants

Ex ante programmability of contributions	Idiosyncracy	Impactedness of information for post hoc performance assessment	Control archetypes
High	Low		Market Control – Control based
	Moderate		on competition  Arm's length Control  (hierarchical or hybrid) – (Quasi) independent: control based on market-derived standards or predefined contractual
	High		provisions  Machine Controls –  Administrative control based on codification of behavior (action oriented) or predefined performance targets (results oriented)
Low	Low	Low	Market Control – Control based on competition
	Moderate	Low	Exploratory Control (hierarchical or hybrid) – Control based on converging insight that accrue and spread during the process. Convergence either administratively induced or based on market-disciplined information sharing
		High	Boundary Control (hierarchical or market-based) – Market procurement if reputation effects are reliable; otherwise proscriptive control of administrative origins
	High	Low	Exploratory Control (hierarchical) – Administrative control based on converging insight that accrue and spread during the process
Source: Speklé 200	24	High	Boundary Control (hierarchical)  – Administrative control through interdictions, emphasizing behavior to be avoided

Source: Speklé, 2001

Analyzing the contingency factors as proposed by van der Meer-Kooistra & Vosselman (2000) within the Lebanese context provides a different outlook in terms of choice of control mechanisms and suggests an incongruence between the control mechanism adopted and the one that would best suit the situation. In fact, whereas the transaction characteristics at all stages of the outsourcing relationship suggest a trust-based control mechanism, the transaction environment somewhat but definitely the party characteristics imply the need for a mix of bureaucracy and trust mechanisms. The fact that the collaboration is characterized by high asset specificity, low repetition, low measurability of output and long-term commitment at all stages reinforces the choice of a trust-based mechanism. The latter is also supported by the finding of high market risks, social embeddedness and institutional factors as well as competence reputation and networking skills. However, the presence of medium risk sharing attitude, asymmetry in bargaining power and information at both contact/contract and execution as well as the lower level of uncertainty in future contingencies at contact/contract suggest the potential for a mix of trust and bureaucracy control mechanisms. This is further corroborated by the proposed control archetype of hierarchical exploratory given low programmability, low impactedness and high idiosyncrasy. This is also in line with the analysis of public sector outsourcing and the need for accountability and transparency (Narayanan et al., 2007) which suggests the need for a combination of control mechanisms. The findings of this section are summarized in table 6.6. Therefore, it would appear that in this particular context the transaction party characteristics as defined by van der Meer-Kooistra & Vosselman (2000) would point

towards the use of a different control mechanisms rather than the one actually employed.

Table 6.6: Contingency factors and interfirm control patterns for each stage in the public private partnership for the governance of organ donation and transplantation in Lebanon

	Contingency Factors	Market- based	Bureaucracy-based	Trust-based
	Transaction Characteristics			High asset specificity, low repetition, low measurability of output, long-term commitment
Contact/Contract	Transaction Environment Characteristics		Medium to high future contingencies	High market risks, high social embeddedness, high institutional factors
	Transaction party characteristics		Competence reputation, medium risk sharing attitude, asymmetry in bargaining power, asymmetry in information, experience in networks	Competence reputation
	Transaction Characteristics			High asset specificity, low repetition, low measurability of output, long-term commitment
Execution	Transaction Environment Characteristics			High future contingencies, high market risks, high social embeddedness, high institutional factors
	Transaction party characteristics		Competence reputation, imbalanced risk sharing attitude, asymmetry in bargaining power and information	Competence reputation, networking

Source: Author's findings

### 6.3.2. Additional contingency factors

As a result of the above analysis, it becomes clear that there are additional factors to be taken into account when exploring the governance and management control mechanisms in the organ donation and transplantation in Lebanon. Ditillo et al. (2015) hypothesized that the choice of control mechanism could be explained by two categories of explanatory variables namely service variables which are essentially derived from transaction cost economics and similar to those previously discussed and additionally relationship variables proposed by contracting out and control decision literature (Ditillo et al., 2015). Service characteristics consist of asset specificity, task uncertainty, task interdependence, and output measurability. Services characterized by high output measurability but low asset specificity, task uncertainty and interdependence are expected to be associated with market-based types of controls while services with low output measurability are expected to be associated with hierarchy based controls if the other three characteristics are moderate and trust based controls if they are high (Caglio & Ditillo, 2008; Ditillo et al., 2015; Håkansson & Lind, 2004; Langfield-Smith, 2008; van der Meer-Kooistra & Vosselman, 2000).

Relation variables include partner knowledge, political visibility, mode of delivery or goal congruence. Market based controls were expected where relation characteristics were low while hierarchical based controls were expected for moderate relational characteristics and trust based controls for high. These characteristics also include control variables such as provider's and municipality size, geographic location, political orientation and financial performance but there were no expectations on their levels.

Hakansson & Lind (2004) explored the importance of combining models of coordination and control in understanding relationships (Håkansson & Lind, 2004). Three types of coordination are proposed namely, hierarchical coordination, market coordination and clan coordination. Whereas hierarchical coordination relies on rules and formal power, the market coordination is based on the market process which act as a main source of information. Finally, the clan coordination builds on tradition, common values and beliefs.

The services and relations explanatory variables proposed by Ditillo et al. (2015) appear to be more in line with the Lebanese situation which combines high asset specificity, task uncertainty and interdependence with low output measurability on the one hand, and high political visibility and partner knowledge on the other.

### 6.3.3. Transaction cost economics and risk

Moreover, in addition to trust, another component to be considered in the study of interorganizational relations is the notion of risk which has become more recently the focus of many studies on collaboration (Caglio & Ditillo, 2021; Das & Teng, 2001; Langfield-Smith, 2008). Two types of perceived risk are specifically distinguished in interorganization alliances. Relational risk measures the risk of lack of cooperation between partners while performance risk refers to the risk of not achieving the partnership's objective regardless of that cooperation. Relational risk is a function of the presence of hidden agendas, private benefits and lack of commitment to the common goals of the collaboration all of which might engender opportunistic behavior.

Performance risk, on the other hand, is based on more contextual factors such as

competition, market fluctuation or a change in government policy. Therefore, high relational risk is a function of high behavioral uncertainty while high performance risk is based on high environmental uncertainty.

In situations where asset specificity and uncertainty are high and the transactions are frequent, both relational and performance risks are perceived as high. In order to control such risks, specific governance structures, control mechanisms and trust would need to be applied (Das & Teng, 2001; Langfield-Smith, 2008). In the Lebanese context, although asset specificity and uncertainty are high, perceived risks were not taken into account as can be seen by exploring the frameworks proposed by Das and Teng (2001) and Langfield-Smith (2008).

### 6.3.4. Transaction cost economics, trust and risk

Das and Teng (2001) proposed an integrated framework for trust, risk and control that illustrates the two-way association between each pair (figure 6.1). This highlights the notion that the three concepts are not static but rather are expected to change as the collaboration develops and matures (Das & Teng, 2001; Langfield-Smith, 2008).

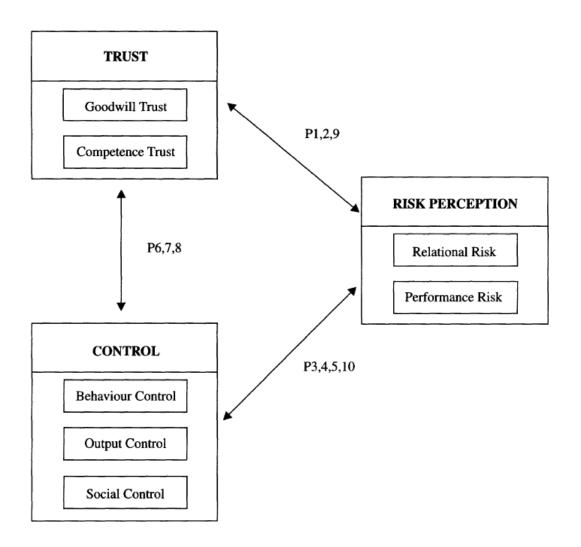


Figure 6.1: Integrated framework of trust, control and risk in strategic alliances

Source: Das and Teng, 2001

Expanding on this idea and combining both trust and risk, Langfield-Smith (2008) proposed a model that explores the determinants of interfirm control mechanisms at the contact phase (figure 6.2). In addition to the effects of risk and trust, the model explores mechanisms through which trust is enhanced and risk is mitigated as part of an effective control package in an effort to account for changes in the levels and association between the three concepts.

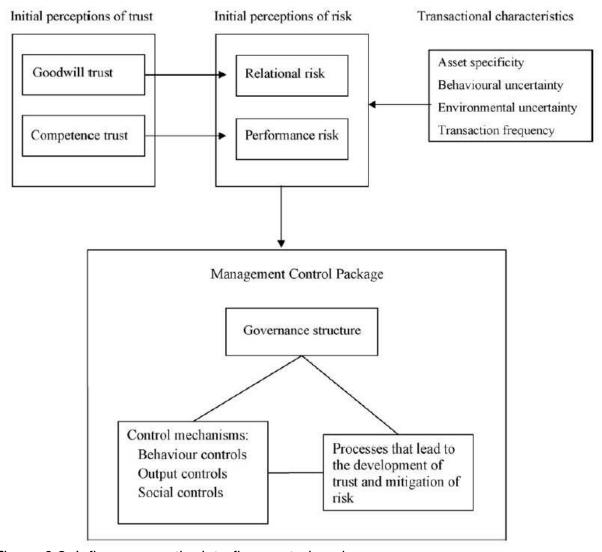


Figure 6.2: Influences on the interfirm control package

Source: Langfield-Smith (2008)

The Lebanese model appears to be quite static with little evolution in the contingency factors or control mechanisms with time. The contact stage appears to be the driver in terms of the performance management of the collaboration and most of the mechanisms that were put in place at the start of the collaboration persisted and remained unchanged with time. Therefore, given the importance of the contact phase, a

further examination of that phase is warranted through the model proposed by Langfield-Smith (2008). Furthermore, this model offers to possibility use a different classification of governance and to integrate the contingency factors as described by Ditillo et al. (2015).

This model posits that at the start of the collaboration, initial perceptions of trust, whether goodwill or competence, and transactional characteristics, such as asset specificity, behavioral and environmental uncertainty as well as transaction frequency, determine the initial perceptions of both relational and performance risk which in turn define the interfirm control package with the governance structure superseding the control mechanisms and processes that lead to trust and the mitigation of risk. The model therefore, highlights the important role of the initial perception of risk in specifying appropriate control patterns.

In this model, governance structures are distinguished in terms of equity (the establishment of an independent self-governing entity owned by two or more partners) and non-equity (contract-based) (Caglio & Ditillo, 2021; Das & Teng, 2001; Langfield-Smith, 2008). Competence trust combines ability and expertise and measures the partner's capacity to perform according to the agreement (Langfield-Smith, 2008; Varoutsa & Scapens, 2018). Goodwill trust, on the other hand, is based on integrity, reliability and responsibility and reflects a partner's intention to perform according to the agreement. Both formal (output and behavior) and informal (social or clan) control structures are proposed (Das & Teng, 2001; Dekker, 2004; Langfield-Smith, 2008).

Formal control can be achieved by means of measuring behavior (process) or outcomes of the behavior (appropriate indicators of output). In essence this consists of establishing rules and regulations to monitor and reward appropriate behavior.

Conversely, social controls are value-based and depend on the creation of common values, beliefs and goals which then serve to reinforce and reward performance alignment. The assumption here is that there will be high levels of motivation and commitment given the internalization of the common goals. Examples of formal and informal control mechanisms are presented in table 6.7.

Table 6.7: Formal and informal control mechanisms used in the alliance

Outcome control	Behavior control	Social control
<ul> <li>Ex-ante mechanisms</li> <li>Goal setting:</li> <li>Strategic goals</li> <li>Short-term goals: cost reductions and ordering</li> </ul>	<ul><li>Structural specifications:</li><li>Ordering and supply procedures</li><li>Functional specifications</li></ul>	Partner selection: Long-lasting joint history and cultural 'fit'
quantities  Incentive systems:  Alliance fund	<ul> <li>Program of innovations</li> <li>Quality planes</li> <li>Specification and division intellectual property rights</li> </ul>	<ul><li>Interactive goal setting:</li><li>Joint governance</li><li>Short-term goals</li></ul>
	Organizational structuring  • Alliance board Task groups	<ul><li>Reputation:</li><li>Trustworthiness RIB for other alliances</li></ul>
	racin groupe	<ul> <li>Trust:</li> <li>Long-lasting relationship</li> <li>Reputation RIB</li> <li>Open book agreement</li> <li>Intentional incomplete agreement</li> </ul>
<ul> <li>Ex-post mechanisms</li> <li>Performance monitoring:</li> <li>Open book accounting cost reductions</li> <li>Rewarding:</li> <li>Benefit sharing</li> </ul>	<ul> <li>Behavior monitoring:</li> <li>Pre-action review of ideas for innovation</li> <li>Board monitoring</li> <li>Auditing use quality plan</li> </ul>	Shared decision making and goal setting:  Joint alliance board  Joint task groups
Source: Dekker, 2004		

The type of control used will depend on two task characteristics namely, programmability and output measurability (Das & Teng, 2001; Langfield-Smith, 2008). When both task characteristics are low, output and behavioral controls are used and the potential for both types of perceived risk is expected to be low (figure 6.3). On the other end of the dichotomy, when both task characteristics are high, the potential for both perceived risks is high and social controls are favored.

# Nowledge of the Transformation Process (i.e. Task Programmability) high low Behaviour control and output control (Performance Risk) Outcome Measurability Behaviour control Social control low (Relational Risk) (Relational Risk and Performance Risk)

Figure 6.3: Control modes and incidence relational risk and performance risk Source: Das and Teng, 2001

The final component of this model consists in the development of trust to reduce potential risks which is far more complex as it is a process that evolves with time and is contingent on developing mutual interests, building trust in systems, institutions and parties and engaging in joint dispute resolutions (Das & Teng, 2001; Greenberg et al., 2008; Langfield-Smith, 2008).

# 6.4. A MODEL FOR DETERMINANTS OF INTERFIRM CONTROL MECHANISMS IN FRAGMENTED HEALTHCARE SYSTEMS IN FRAGILE SETTINGS: DOMINANCE OF TRUST AND ABSENCE OF PERCEIVED RISK

Although intuitive, the model proposed by Langfield-Smith (200\*) does not mirror the Lebanese reality. As explained earlier the main trigger for the particular governance structure in the case of the PPP for organ donation and transplantation was in essence the country context at the time of the inception of NOD-Lb and the start of the collaboration. In fact, there was a need for a service that the MoPH could not provide due to lack of resources and therefore the decision was taken to collaborate with a private entity that was specifically developed for this purpose. The health system reforms and the drive towards collaborative governance based on previous experience as well as the role of personal relations and informal arrangements in the Lebanese culture provided the necessary ingredients for setting up the governance mechanism which underlined the interfirm control processes at the time. Trust both goodwill and competence was the main determinant of choice. It is probably because of the importance of trust, that risks were either perceived as low or ignored in an attempt to get the process off the ground. However, it would also appear that the trend continued, and no risk assessment was incorporated later at contract or implementation where trust continued to dominate with informal control measures. Attempts to organize, legalize or structure were blocked by legislation and financial constraints. Another factor that seems to come into play in determining the control mechanisms in the Lebanese situation would be the explanatory variables particularly the relational

ones that were not originally included in the Lagfield-Smith model. Therefore, it would seem that both governance and control mechanisms are determined by trust and explanatory variables and then remain static for the duration of the PPP in the absence of processes to improve trust and mitigate risk. This could also potentially be explained by the fact that trust and social controls seem to override the entire process despite the fact that the ultimate goal is the provision of a public service with all that it entails in terms of accountability and transparency. Governance does not seem to have any impact on control mechanisms. This coincides with the PMSs framework analysis where formal performance evaluation mechanisms were non-existent.

The Lebanese situation suggests that models aiming at influencing interfirm control mechanisms are culture-specific and might not be arbitrarily generalizable (Steenkamp & Geyskens, 2012). This would imply adding both service and relational contingency factors to the model proposed by Langfield-Smith (2008) as well as investigating the potential influence of other societal indicators such as power distance, self-expression and secular rational values. It has been shown that the extent to which TCE explains interfirm control choices varies according to national culture as governance choices based on economic considerations are contingent on the cultural context in which they are applied (Steenkamp & Geyskens, 2012). This situation rejoins the public health discourse on the importance of social determinants of health (Lombrail, 2013) and given that organ donation and transplantation is a public health issue, this would suggest the importance of incorporating these elements into the model.

Finally, given that the governance structure has no impact on the management control mechanisms in the Lebanese context, it is not surprising that the model does not provide a better classification than was previously obtained. In fact, the governance structure in the Lebanese case cannot be described in terms of equity or non-equity. The PPP between MoPH and NOD-Lb is definitely not contract-based and although NOD-Lb is an independent entity, it is not owned by two or more partners. Therefore, the closest characterization for the governance structure in the case of the PPP for organ donation and transplantation in Lebanon remains that of hierarchy given that it was instituted by a law.

Figure 6.4 presents a reformulation of the model proposed by Langfield-Smith that incorporated the findings based on the Lebanese model for the PPP for the governance of organ donation and transplantation. Items shaded in yellow are added while those in red are missing.

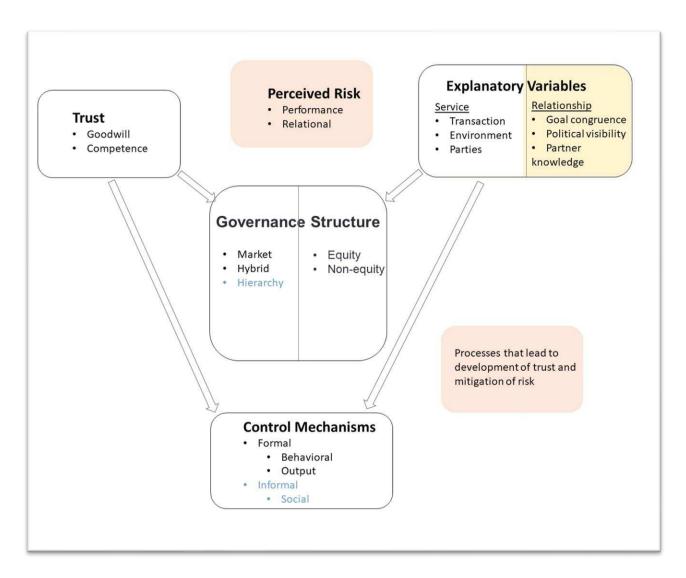


Figure 6.4: The Langfield-Smith model for influences on interfirm control mechanisms adapted to the PPP for the governance of organ donation and transplantation in Lebanon

Source: author's findings

In conclusion, revisiting the PPP-based governance structure between NOD-Lb and the MoPH using an adaptation of the Langfield-smith model, clearly highlights the static nature of the governance mechanism in Lebanon which remains the same as it was on

the day that NOD-Lb was established. At that time, given the political and economic context, the fragmentation of the health system, the lack of skilled human resources in the MoPH and the high levels of both goodwill and competence trust, a Ministerial decree was issues creating NOD-Lb as a regulator for the organ donation and transplantation system in Lebanon and instituting a PPP-based governance structure which can best be described as hierarchical. The only control mechanisms employed appear to be informal, social controls. However, in the delivery of public goods where transparency and accountability are important considerations, more formal controls are also warranted.

Furthermore, the Lebanese model is characterized by high asset specificity and uncertainty and as thus should have incorporated an assessment of risk at least at the contact stage. Having said that, it is clear from Figure 6.4 that the Lebanese model does not allow for the assessment of perception of risk and does not incorporate mechanisms to build trust and mitigate risks. In fact, whereas the governance mechanism is usually contingent on the impact of trust and transaction characteristics on risk, in Lebanon the risk assessment appears to be missing or ignored possibly due to the strength of the trust and external explanatory variables. This is also evident in the analysis of performance management based on the PMSs framework which shows no performance evaluation and therefore no opportunity to learn and grow.

# **CONCLUSION**

Organ shortage, although a major public health problem can also be viewed as a performance management problem in need of good management, governance, collaboration and regulation. The general intent of this research was to gain a better understanding of the process of organ donation and transplantation through a close scrutiny and an in-depth exploration of its performance management. Using an interpretative paradigm, a qualitative approach and a case study methodology, the specificities and limitations of the Lebanese organ donation and transplantation process were explored in an attempt to answer the following research question: "What performance management model can be proposed for an organ donation and transplantation system in a fragmented and fragile healthcare context?" More specifically, this thesis attempts to answer the following four questions:

- 1. How can the performance of an organ donation and transplantation system be defined?
- 2. What performance issues can be identified in an organ donation and transplantation system in a fragmented and fragile healthcare context?
- 3. How can a PPP-based governance and regulation solution to the performance management issues of organ donation and transplantation be analyzed?
- 4. What could be the contribution of interorganizational control literature to address PPP-based governance and regulation issues for organ donation and transplantation?

### 1. CONTRIBUTIONS

The thesis offers several contributions on the managerial, theoretical, methodological and practical perspectives.

From a **managerial** perspective, the main contribution of this thesis consists in exploring the organ donation and transplantation system in a fragmented healthcare setting from a performance management perspective. In fact, this thesis addressed a public health problem from an organizational perspective by using a performance management lens to analyze the governance, regulation and interorganizational control mechanisms inherent in the system. Organ shortage is one of the major public health challenges of the century (Koh et al., 2007). In fact, according to Cantarovich (2018), "organ shortage is a social, psychological, ethical, moral and political problem, causing unjustifiable damage to public health" (Cantarovich, 2018). The literature on organ donation and transplantation, though abundant, has mostly focused on the ethical and marketing perspectives associated with organ shortage while management issues were left lagging behind (Manzano & Pawson, 2014; Mercado-Martínez et al., 2013; Razdan et al., 2015). From an ethical perspective, research has concentrated on legislature, religion and the philosophical discourses on altruism, the act of giving, health inequalities and organ selling and trafficking (Bilgel, 2011; Chan, 2020; Modra & Hilton, 2015; Rutty, 2016). From a marketing perspective, the focus was more on factors that increase public awareness and willingness to donate including family consent and health professionals' attitudes (de Groot et al., 2015; dos Santos & Feito, 2018; Findlater & Thomson, 2015; Jawoniyi et al., 2018; Laughlin et al., 2021; Marck et al.,

2016; Mercado-Martínez et al., 2013; Ralph et al., 2014; Vargas et al., 2017; J. Weiss et al., 2014; Wong, 2010).

This thesis has positioned organ donation and transplantation in the realm of organizational research by considering organ donation and transplantation as a multifaceted process that depends on a series of steps that cannot function independently thus making improving the whole dependent on understanding and coordinating its parts (Manzano & Pawson, 2014; Miranda, Lucas, et al., 1999). Organ transplantation has been described as a complex adaptive system that continuously faces the challenge of matching supply to demand under the constraints of time and resources (Manzano & Pawson, 2014).

More specifically this thesis has addressed the concept of governance of organ donation and transplantation which although on the forefront of most public health discussions (Mikkelsen-Lopez et al., 2011; van Olmen et al., 2012); (Siddiqi et al., 2009); (D. W. Brinkerhoff & Bossert, 2014; Chanturidze & Obermann, 2016) has been lacking in the organ donation and transplantation research. The literature analyzing organ donation and transplantation from an organizational perspective has mostly focused on the process within the hospital (Freire et al., 2015; D. H. Howard et al., 2007; Marck et al., 2016; Mercado-Martínez et al., 2013; Razdan et al., 2015; Siminoff & Traino, 2009). However, the organ transplantation process is multifaceted and involves components that have more macroeconomic dimensions related to the organizational and legal aspects of the country (Mizraji et al., 2014). Moreover, a systematic review

has clearly highlighted the central role of organization at all levels in the organ donation and transplantation continuum from government to hospital to citizens (Triassi et al., 2014).

The problems with the organ donation and transplantation process as highlighted by NOD-Lb clearly point to issues with decision-making and regulation which are consistent with the governance of the system. In fact, the framework proposed by Mikkelsen-Lopez et al. (2011) demonstrates that governance impacts on all other components of health system performance namely financing, medicines and technology, human resources, information and eventually service delivery.

In terms of governance, this thesis has also delved into the NPM theories by contributing to the literature on PPPs and regulatory agencies. This thesis has added to the ongoing research on collaboration between state and not-for-profit organizations as well as the role of agency. Originally, most studies on PPP were concerned with infrastructure or environmental issues while PPPs for healthcare have only recently begun to infiltrate the literature. Therefore, this study adds a new twist to the application of PPP within the health context as the PPP established between the MoPH and NOD-Lb is atypical in that it is not contingent on a contract and has no binding deliverables or time limitations. Moreover, NOD-Lb is more of a third sector organization that is financially dependent on the public sector. The PPP established between the MoPH and NOD-Lb was analyzed through a scrutiny of the relationship, trust, commitment and

stability components. This analysis has required the integration of several theories into the framework used to assess the characteristics of the PPP.

Similarly, in understanding the role of NOD-Lb as a regulatory agency it was important to combine components of both agency and stewardship theories to present a new profile for a regulatory agency that is contingent on context. Again, due to the atypical nature of the PPP, the characteristics of the regulatory agency do not clearly follow the dictates of the agency theory making it necessary to search for explanations by studying the cultural components and applying stewardship concepts.

Finally revisiting the management control literature, has positioned the analysis of the PPP for the governance of organ donation and transplantation as a potential management control problem by highlighting the importance of the service and relation characteristics as well as the roles of trust and perceived risk in the choice of governance within a particular cultural context. Applying TCE and combining the notions of trust, risk and relational variables led to the elaboration of a contextual model for exploring the influences on management control mechanisms for the organ donation and transplantation system in a fragmented healthcare setting.

From a **theoretical** perspective, this study has added to the literature on the monitoring of public services in contracting out contexts by incorporating relational explanatory variables with transaction-cost economics (Ditillo et al., 2015). Therefore, this study served to complement the analysis of the governance of organ donation and

transplantation systems in the light of transaction cost economics theory by including in the set of explanatory variables relational ones particularly applicable for fragmented and fragile contexts. In addition, delving into the public sector literature and arguing the merits of New Public Governance frameworks in explaining the role of governance on performance management in service delivery of public goods

From a **methodological** point of view this thesis has attempted to study organ donation and transplantation using a qualitative approach and a case study methodology. Most of the literature on organ donation and transplantation to date being of a more epidemiological nature has focused mostly on numeric information and statistics (Matesanz, Domínguez-Gil, Coll, Rosa, & Marazuela, 2011) relative to deceased donor potential (Goldberg et al., 2017) conversion rates (Wynn & Alexander, 2011), consent rates (Koh et al., 2007) and the number of donors gained or lost at each phase (Domínguez-Gil et al., 2011; Graham et al., 2009). In addition, most studies have been underpinned by a post-positive paradigm and conducted using quantitative approaches.

More specifically, the case study approach allowed in-depth exploration and deep dives into the issues surrounding the inception of the regulatory agency and the challenges that it routinely faces. It also allowed a better understanding of the contextual and contingent factors that underpin the collaboration between NOD-Lb and the MoPH. In order to obtain a holistic picture, it was important to study the collaboration in its natural context and construct its reality based on testimonies and perceptions of the concerned parties. The case study has also allowed for further development of accounting and

control theory through a process of theoretical generalization (Yin, 2014) and a refinement of an existing model.

From a **practical** perspective the contributions of this thesis consist in providing a model for describing the influences on management control adapted to the PPP for the governance of organ donation and transplantation in a fragmented healthcare system in a fragile context. This thesis has also suggested the use of several frameworks for describing the regulatory agency, the collaboration in the PPP for the governance of organ donation and transplantation, the governance and the performance management systems in organ donation and transplantation. Finally, this thesis has contributed to the analysis of an organ donation and transplantation system in a fragmented healthcare system in a fragile context. The bulk of the research on organ donation and transplantation comes from the developed countries in the Global North. However, this thesis has clearly developed the additional challenges of a fragmented healthcare and fragile context. The results of this work clearly show that context is important and understanding the context in which a PPP is to be developed or a program (such as the organ donation and transplantation program) is to be implemented is primordial. It is not possible to transport systems from one place to another without properly understanding and accounting for the societal and cultural components. The same applies to the literature on TCE as applied to management control mechanisms.

### 2. IMPLICATIONS

Several recommendations disaggregated on three levels namely, the MoPH, the regulatory agency NOD-Lb and the society at large, emanate from the analysis presented in this thesis.

At the ministry level it is important to develop evolving inter-organizational control mechanisms guided by a governance mechanism that incorporates an assessment of perceived risk as well as processes that promote the building of trust and the mitigation of risks. The importance of trust in the choice of governance mechanisms in Lebanon suggests the need for further analysis trust issues that go beyond trust in parties and include an analysis of the determinants of trusted systems and trusted institutions (Greenberg et al., 2008).

The organ donation and transplantation system needs to develop proper performance management systems that include a solid strategic plan with targets, performance indicators and more importantly performance evaluation mechanisms and a clear understanding of how PMSs and used and bring about change.

This effort which started as a civic society initiative due to a weak public system and lack of expertise, needs to evolve into a public service provided by the government. To do so, the MoPH needs to embrace the program as part of its national health plan and develop within the necessary capacities and expertise to lead the program at a policy

level while delegating the implementation to a private entity in the spirit of a public private partnership where the partner has full support and is afforded power to implement the necessary tasks. There should be a department within the MoPH concerned with organ donation that includes professionals with proper expertise to give educated opinions and make informed decisions.

The collaboration between the MoPH and NOD-Lb needs to extend beyond personal meetings between two or three individuals. It should be formalized to become more of a collaboration than an act of seeking approval and ratification. In addition, meetings should be planned regularly and should include both national and regional coordinators.

To ensure proper funding of the system and reimbursement as well as control and power over the various components, there is a need to promote universal health care that encompasses organ donation and recognizes the need for it and its importance. Proper financial incentives need to be studied and proposed in Lebanon especially as most health professionals in Lebanon are found in private hospitals it is important to promote procurement and transplantation activities in public hospitals through a twining project with the private hospitals. Private hospitals can also be encouraged to participate through reimbursement incentives and quality control programs.

The objectives and goals of the partners should be properly aligned in order to create value and offer a much-needed service. For the process to function properly it requires

adequate support, resources and infrastructure all of which are contingent on the commitment of both partners. The process should be afforded a stability that is independent of the financial and political situations of the country. The budget and support provided by the MoPH should not be contingent on the year and/or political agenda and affiliations of the MoH.

In terms of the regulatory agency, efforts should be invested in decentralization of efforts, redistributions of roles and division of labor. The implementation of the organ donation process cannot depend on the will of a few select dedicated people but has to become a full-fledged exercise in collaboration that includes society as a whole.

Moreover, there should be a built-in system of quality assurance and accountability engaged in as part of the collaboration and coordination process. It should be undertaken as a learning experience in order to foresee potential breaks in the process and implement improvements.

In terms of the society, health professionals and hospital administrators should be more invested and participate more actively in the process. Both the regional and local coordinators should be empowered and allowed to engage at a higher level. They should be properly remunerated for their efforts but they should also understand the importance of the tasks at hand and the greater value of their role in saving lives.

Judges need to be better trained and efforts need to be deployed to clear cases in a timely manner to avoid loss of organs or limiting family consent.

The media should be more involved and information properly channeled. In the spirit of raising awareness and promoting transparency the media should be trained, regularly informed and actively engaged in activities relating to organ donation and transplantation. Organ donation is not all about scoops and emotions. Finally, the Lebanese society needs to be empowered and informed. People need to understand the importance of the program and be allowed to contribute to the process. This could be achieved by involving the public in the decision-making and planning process (Danet et al., 2021).

### 3. STRENGTHS AND LIMITATIONS

Research is always characterized by strengths and limitations which have a direct bearing on the internal and external validity of the study. The strength of this research lies in the use of a rigorous qualitative approach to explore a public health issue from an organizational perspective. The use of a case study allowed for a detailed description of the context of the study as well as the provision of a historic overview of the health system in general and the organ donation and transplantation system in particular. The collection of information from different sources and using different methods added to the completeness of the findings while the use of member checking and triangulation enhanced their validity. Moreover, the ease of access to the field and the positive attitude of the study participants, their willingness to collaborate and their availability for lengthy formal and informal interview sessions has added to the wealth and quality of the information collected.

The findings of this research should be viewed with some limitations in mind. This study is a case study focused on NOD-Lb and therefore, it would be difficult to transpose the findings of this study, unilaterally, to other contexts. This, however, was not the objective of this study where the intent was to do an in-depth exploration of a system within a particularly challenging context. The findings could be cautiously applied to other countries with similar characteristics. Another limitation of this analysis is that the comparative study was based on documentation and is therefore, limited to what was available on the web and in the databases consulted. The nuances in the information are also contingent on the documents consulted and the emphasis that they provided. However, the quantity of articles and websites consulted for each country has afforded this work with a certain level of objectivity in the information provided.

### 4. FUTURE RESEARCH

This study serves as a catalyst for future research on the governance of organ donation and transplantation. More can be done on the domains of governance including strategic vision and policy, consensus and participation, addressing corruption, being accountable and being transparent. This thesis touched upon these concepts as they were revealed in the interviews but within the context of a newly developed PPP concept and a country in fragility and transition each one merits a study on its own. Within the PPP framework, more work can be done on collaboration by further analyzing the trust component and power structures that govern the relationship between the public and private organizations. This is especially important in fragile countries with high power distance and unstable political contexts. Similarly, the shared

goals and creation of value merit a closer scrutiny. This is important not only in the definition of the collaboration but also in understanding of the role of the principal and agent/steward. Commitment is another concept that can be further investigated especially as its understanding varies from one person to the next. It would be interesting to compare within the context of the PPP the understanding of commitment by different parties in conjunction with their actions to reinforce the sentiment.

Most of the research on interorganizational relations and outsourcing alliances has focused on trusted parties ignoring other sources of trust including trusted systems and trusted institutions. These forms are culture specific and require further investigation in different environments. For example, situations with unstable political and economic conditions or heavy public corruption are bound to warrant different forms of management control mechanisms.

In terms of process, there is more to the process of organ donation and transplantation than governance. Although this study focused on the national level, there is more to be done on the regional and local levels. In fact, very little has been done in terms of the process at the regional level.

In addition, although this thesis used a qualitative approach, it would be interesting to reinforce the findings by using quantitative methods to quantify the association between trust, risk, governance and control mechanisms as well as test the significant contribution of different contingency variables on governance. It would also allow the

investigator to measure the relative contribution of trust, commitment and stability to the PPP.

Finally, comparative and/or experimental studies would also inform the field on best practices and allow the evaluation of specific application and their impact on the organization of the process.

### 5. CONCLUDING REMARKS

This thesis has analyzed organ donation and transplantation from a performance management perspective by focusing on the problem of organ shortage and linking the solution to governance, regulation and management control mechanisms. Moving beyond the traditional literature on organ donation and transplantation that dwells on legislature, religion and ethics as well as attitudes of donors and health professionals, this thesis applied a management lens to the problem. Organ donation and transplantation was portrayed as a complex multifaceted process (Mizraji et al., 2014) where organization plays a central role at all levels in the organ donation and transplantation continuum from government to hospital to citizens (Triassi et al., 2014).

Revisiting the contracting out & interorganizational control literature positioned the analysis of the PPP within the realm of performance management controls and the determinants of the choice of control mechanisms. This allowed the analysis of the case from the perspectives of accounting, economics and social theories and highlighted the

importance of context, perceived trust and risk and well as the incorporation of processes to develop trust and mitigate risk as the collaboration evolves with time.

A case study methodology allowed an in-depth exploration of the governance of the process of organ donation and transplantation in Lebanon embodied by a PPP established between the MoPH and the regulatory agency NOD-Lb. Applying NPM theories for collaboration and agency, the collaboration between the state and the third sector can be described as a partnership based on mutuality and organizational identity that is built on foundations of personal relations and trust but lacks an institutionalized framework and a true sense of commitment and stability. Given this collaborative structure, the regulatory agency mostly displays stewardship characteristics with some embedded agency components. These findings provide insights on organizational constraints that might hinder the process of organ donation and transplantation. Broadening the horizons by taking the management of the system into account could provide venues for improvement that were expected but not forthcoming in the traditional approach towards organ donation and transplantation. In conclusion, when approaching the problem of organ shortage, it is important to develop a holistic strategy that tackles all perspectives rather than focusing on just one aspect.

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Titre: Management de la performance basée sur un partenariat public-privé pour des systèmes de santé fragmentés: le cas du don et de la transplantation d'organes au Liban

**Mots clés :** don et transplantation d'organes, partenariat public-privé, agence de régulation, contrôles inter-organisationnels, gestion de la performance, gouvernance

Dans un contexte de pénurie d'organes, le don et la transplantation d'organes se positionnent comme un problème de management de la performance avec des besoins spécifiques en termes de gestion, de gouvernance, de collaboration et de régulation. Cette recherche cherche à répondre à la question suivante « Quel modèle de gestion de la performance peut-on proposer pour un système de prélèvement et de transplantation d'organes dans un contexte de santé fragmenté et fragile ? » Le cas libanais a été retenu pour étudier cette question à partir d'une étude de cas portant sur l'agence de régulation libanaise et sa collaboration avec le Ministère de la Santé Publique dans un contexte de fragilité.

Apres avoir developé l'intérêt d'aborder les problèmes des systèmes de prélèvement et de

transplantation d'organes nous analysons les differents modèles existant dans le monde qui mettent en evidence les questions de gouvernance comme un maillon central. Ce travail explore le partenariat public-privé, que constitue l'agence de regulation libanaise, comme une solution aux problèmes de management de la performance. Dans un dernier temps les problèmes de gouvernance soulevés par cette solution sont examinés au l'aune de la littérature en contrôle interorganisationnel.

Ce travail contribue à une meilleure compréhension des contraintes organisationnelles susceptibles d'entraver le processus de don et de transplantation d'organes dans un contexte de soins de santé fragmenté et fragile.

Title: Public private partnership-based performance management in fragmented healthcare systems: The case of organ donation and transplantation in Lebanon

**Keywords:** organ donation and transplantation, public private partnership, regulatory agency, interorganizational controls, performance management, governance

Abstract In an era of organ shortage, organ donation and transplantation are identified as a performance management problem with specific needs in terms of management, governance, collaboration and regulation. This research seeks to answer the question: "What performance management model can be proposed for an organ donation and transplantation system in a fragmented and fragile healthcare context?" The Lebanese fragile context was retained to study this question based on a case study of the Lebanese regulatory agency and its collaboration with the Ministry of Public Health.

Having established the interest of addressing challenges of organ donation and transplantation systems from a performance

management perspective, an analysis of different exiting models underscores governance as a central issue. This thesis explores the public private partnership, the governance structure adopted in the Lebanese situation, as a solution to performance management problems. Finally, PPP-based governance challenges highlighted by this case are revisited in the light of the interorganizational control literature.

This work contributes towards a better understanding of the organizational constraints that might hinder the process of organ donation and transplantation in a fragmented heathcare setting.