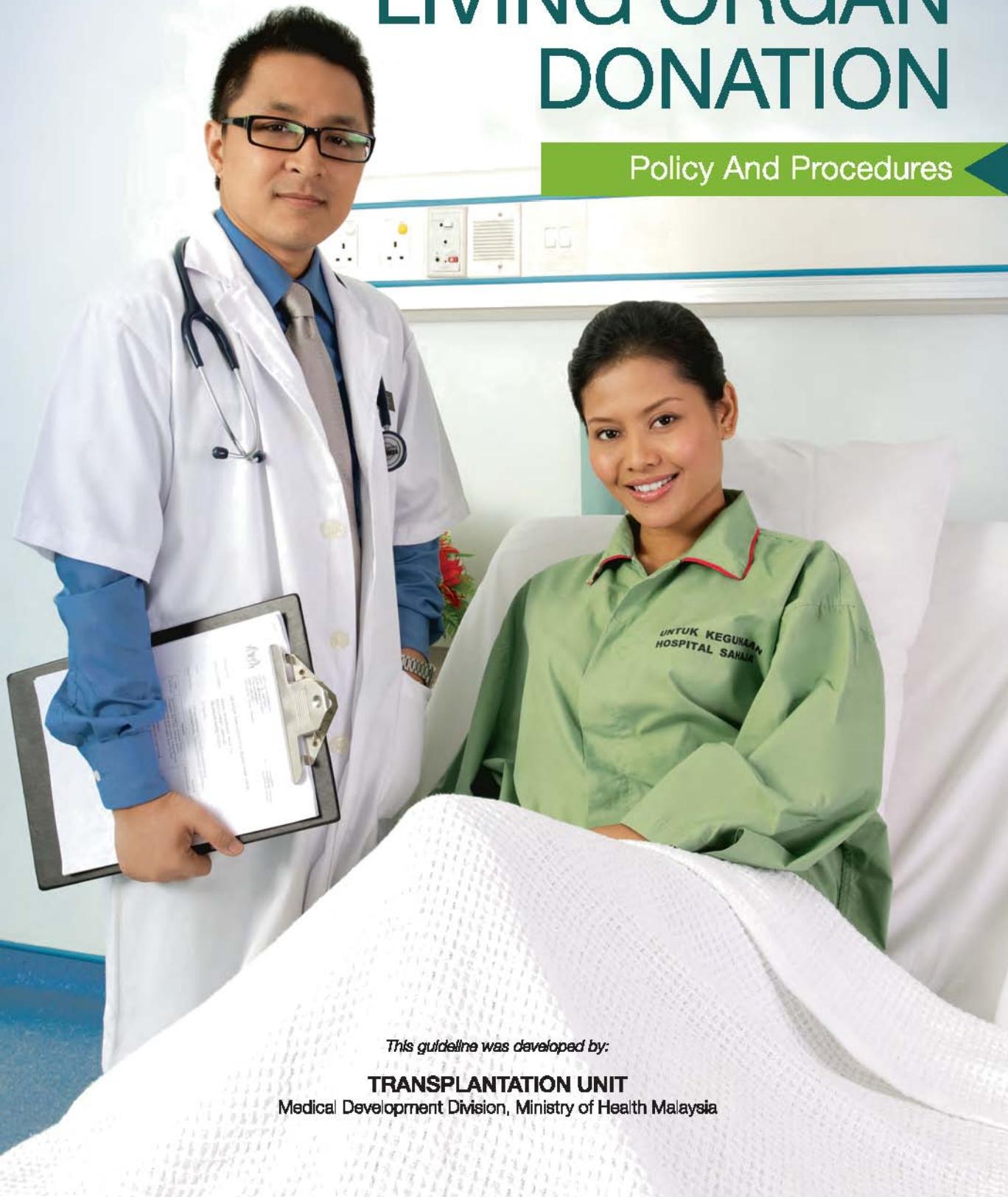


UNRELATED LIVING ORGAN DONATION

Policy And Procedures



This guideline was developed by:

TRANSPLANTATION UNIT

Medical Development Division, Ministry of Health Malaysia

UNRELATED LIVING ORGAN DONATION:

Policy And Procedures



This guideline was developed by:

TRANSPLANTATION UNIT

Medical Development Division, Ministry of Health Malaysia

First published in Malaysia in 2011 by

Transplantation Unit
Medical Development Division, Ministry of Health Malaysia
Level 5 Block E1 Complex E
Federal Government Administrative Centre
62590 Putrajaya Malaysia

Tel : (603) 8883 1165
Fax : (603) 8883 1155
Email : transplantation_unit@moh.gov.my

© The Ministry of Health Malaysia 2011
www.moh.gov.my

Institute for Medical Research Cataloging in Publication Data
A catalogue record for this book is available from the Institute for Medical Research,
Ministry of Health Malaysia

National Library of Malaysia Cataloging in Publication Data
A catalogue record for this book is available from the National Library of Malaysia

MOH/P/PAK/221.11 (BP)

ISBN 978-983-3433-99-5

A standard linear barcode representing the ISBN number 978-983-3433-99-5.

9 789833 433995

All rights reserved: no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise without the prior permission of the Ministry of Health Malaysia.

ORGAN DONATION IS A GIFT OF LIFE

www.agiftoflife.gov.my

CONTENT

List of Figures, Tables and Appendix	ii
Glossary	iii
Foreword	
Foreword by the Director General of Health Malaysia	vii
Foreword by the Deputy Director General of Health (Medical)	viii
Policy and Procedures (Section)	1
1. Purpose of guidelines	3
2. Objectives of guidelines	3
3. Introduction	3
4. Definition	4
5. Policy	5
6. Assistance to a living donor	6
7. General guidelines	7
8. Unrelated Transplant Approval Committee (UTAC)	8
9. Independent Donor Advocates Team (IDAT)	9
10. Secretariat of UTAC	10
11. Procedures of application	11
Bibliography	18
Appendix	19

LIST OF FIGURES, TABLES AND APPENDIX

FIGURES

Figure 1: Types of Living Organ Donation that Require UTAC Approval	6
Figure 2: The 4 Basic Steps in Applying for UTAC Evaluation	11
Figure 3: Flowchart of Process for UTAC Application	17

TABLES

Table 1: Summary on Degree of Consanguinity	5
Table 2: Forms to be Filled in by the Applicant	13
Table 3: Forms to be Filled in by Members of the Independent Donor Advocates Team (IDAT)	15

APPENDIX

Appendix 1: Checklist A (Secretariat)	21
Appendix 2: Checklist B (Applicants)	27
Appendix 3: Form A (UTAC): Application for Living Unrelated Transplant	31
Appendix 4: Form B (UTAC): Declaration by the Prospective Living Donor	41
Appendix 5: Form C (UTAC): Declaration by the Prospective Recipient	49
Appendix 6: Form D (UTAC): Donor Evaluation: Report by Donor Advocate (Medical)	57
Appendix 7: Form E (UTAC): Donor Evaluation: Report by Donor Advocate (Psychiatrist)	65
Appendix 8: Form F (UTAC): Donor Evaluation: Report by Donor Advocate (Medical Social Work Officer)	77
Appendix 9: Translated Form – Borang B (UTAC): Deklarasi oleh Bakal Penderma	95
Appendix 10: Translated Form – Borang C (UTAC): Deklarasi oleh Bakal Penerima	103
Appendix 11: Public Information Leaflet – Living Organ Donation	111
Appendix 12: Declaration of Conflict of Interest and Confidentiality (UTAC Members/Technical Advisors)	127
Appendix 13: Declaration of Conflict of Interest and Confidentiality (IDAT)	131
Appendix 14: Format for Case Summary	135
Appendix 15: Filing System: Arrangement of Documents	141

GLOSSARY

DA-M	: Donor Advocate – Medical
DA-Psy	: Donor Advocate – Psychiatrist
DA-SW	: Donor Advocate – Medical Social Work Officer
DG	: Director General
DVT	: Deep Vein Thrombosis
GODT	: Global Observatory on Donation and Transplantation
HKL	: Hospital Kuala Lumpur
IC	: Identity Card
IDAT	: Independent Donor Advocate Team
JPA	: Jabatan Perkhidmatan Awam (Department of Civil Service)
KP	: Kad Pengenalan
KWSP	: Kumpulan Wang Simpanan Pekerja (Employees Provident Fund)
MMC	: Malaysia Medical Council
MPM	: Majlis Perubatan Malaysia (Malaysia Medical Council)
NHS	: National Health Service
NTRC	: National Transplant Resource Centre
PERKESO	: Pertubuhan Keselamatan Sosial (Social Security Organisation)
UTAC	: Unrelated Transplant Approval Committee
UTI	: Urinary Tract Infection
WHO	: World Health Organization

Foreword





DATO' SRI DR HASAN ABDUL RAHMAN
Director General of Health Malaysia

FOREWORD

BY THE DIRECTOR GENERAL OF HEALTH MALAYSIA

The huge imbalance between demand for and supply of organs from deceased donors has resulted in many people seeking for alternative supply from living persons. These include strangers (unrelated people) and also sourcing organs from other countries, especially from the underprivileged societies. The practice of unrelated living organ donation has triggered many ethical arguments and these include the notion that it has compromised the basic principle of medical ethics of doing no harm (nonmaleficence). Those in lower socioeconomic groups have a higher risk of being manipulated and this goes against the principles of human dignity and human rights.

The organ donation rate in Malaysia is only around 0.64 donations per million populations. On the other hand, it is estimated that as many as 11,000 people are waiting for organs in this country. Because of this huge disparity, it is reasonable for the Ministry to take proactive measures to prevent any possible commercial transaction in exchange for an organ especially in a transplantation involving unrelated living donor. These measures include formulation of the National Organ Tissue and Cell Transplantation Policy in 2007. The Policy has mandated the establishment of Unrelated Transplant Approval Committee (UTAC) to serve as a focus group to preserve the ethical principles of living organ donations and to safeguard the interest of prospective living donors.

Apart from providing care to our patients, it is also the responsibility of the Ministry to promote public health in general. It is hoped that the publication of this document will help to promote health for both the prospective recipient and the prospective donor. I would like to commend the Medical Programme especially the Medical Development Division and the transplant fraternity for developing this guideline.

Thank you.



DATUK DR NOOR HISHAM ABDULLAH
Deputy Director General of Health (Medical)

FOREWORD

BY THE DEPUTY DIRECTOR GENERAL OF HEALTH
(MEDICAL)

The publication of this document is part of the Ministry's commitment to implementing the recommendations of the WHO's Guiding Principles on Human Cell, Tissue and Organ Transplantation. The World Health Assembly in 2010 has urged all Member Countries including Malaysia to enforce internal policies and legislation pertaining to transplantation activities in accordance with the Guiding Principles. At present, there's a strong move by the international community to fight against the commercialisation of human parts, human/organ trafficking and transplant tourism. Our country shares that sentiment and the Ministry of Health will always play a leading role in preserving good medical practice in our profession.

This document will serve as a guide to all healthcare personnel in both the public and private sectors. The document outlines the basic principles of the policy and procedures in transplantation involving unrelated living donors. The interests of the living donors, the recipients and also our profession have to be carefully examined before an approval can be given to a particular case.

It is important for us to maintain the confidence of the public on the integrity of our healthcare system. The policies and procedures on unrelated living organ donation are not to promote bureaucracy in government agencies. Rather they are intended to preserve ethical principles, professionalism in medicine, human rights and dignity in accordance with international standards/ recommendations.

Thank you.

Policy & Procedures



POLICY AND PROCEDURES

SECTION 1: PURPOSE OF GUIDELINES

The purpose of this guideline is to describe the policies and procedures in living organ donation involving persons who are not genetically related. The guideline also explains the rationale of having such policies and procedures.

This is not a clinical practice guideline for the management of living organ donation and transplantation. It does not cover the donation of regenerative tissues from living persons.

SECTION 2: OBJECTIVES OF GUIDELINES

1. To safeguard the interest and welfare of living organ donors.
2. To preserve ethical and professional standards in organ donation and transplantation in the country.
3. To ensure living donors are adequately and appropriately informed about the surgical procedures in line with the principle of informed consent.
4. To ensure living donors receive adequate and appropriate medical, psychiatric and psychosocial evaluation before the surgical procedures.

SECTION 3: INTRODUCTION

The organ donation rate especially from cadaveric donors remains low in Malaysia. In 2010, there were 38 cadaveric donors. As reported by the World Health Organization (WHO) through the Global Observatory on Donation and Transplantation (GODT), Malaysia's deceased organ donation rate is equivalent to 0.64 donations per million populations. On the other hand, it was estimated that as many as 11,000 patients were waiting for organs in our country. Therefore, current organ donation rate is unable to meet the increasing demands. The low organ donation rate is not only a problem in this country but also in the rest of the world including the developed countries.

Organs from living donors provide an alternative source of transplantable organs. In Malaysia, 80% of kidneys for transplantation are sourced from living donors. Some patients even resort to seeking organs from living donors in other countries. However, there are several issues pertaining to the use of organs from living donors:

1. Even though, organ procurement surgery has become a standard procedure, it has its own inherent risks and hence the use of living donors needs extra caution. The donor mortality for kidney donation is around 3.1 deaths for every 10,000 donations. The donor mortality for liver donation is around 1 death in 200 donations for right lobe donations and 1 death in 1,000 donations for left lobe donation. The mortality rate may be considered small but death of a loved one is devastating to family members and must not be

taken lightly. A living donor is an otherwise healthy individual who does not require any medical or surgical intervention. It has been argued that retrieval of organs from such healthy living donors goes against the basic principle of medical ethics of non-maleficence (or do-no-harm). However such relatively smaller adverse possibility is accepted for the greater good which is expected to result from a successful transplantation.

2. The huge disparity between the supply and demand of organs has resulted in various unethical practices including the commercialisation of organs supply and transplantation. This can result in the exploitation of individuals from the lower socioeconomic groups and therefore disrespect human dignity and individual rights of human beings. Commercialisation of organs, along with the related traffic of human beings has become more evident in recent years. It is now one of the major concerns of the World Health Organization and The Transplantation Society (TTS). It is for this reason that the World Health Assembly has endorsed the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation in May 2010. The Guiding Principles emphasise among others on the need for

Donation from deceased persons should be developed to its maximum therapeutic potential, but adult living persons may donate organs as permitted by domestic regulations. In general living donors should be genetically, legally or emotionally related to their recipients.

Live donations are acceptable when the donor's informed and voluntary consent is obtained, when professional care of donors is ensured and follow-up is well organized, and when selection criteria for donors are scrupulously applied and monitored. Live donors should be informed of the probable risks, benefits and consequences of donation in a complete and understandable fashion; they should be legally competent and capable of weighing the information; and they should be acting willingly, free of any undue influence or coercion.

Guiding Principle 3: WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation

member countries including Malaysia to formulate and enforce internal policies and legislation through an effective regulatory mechanism to safeguard the ethical and professional practices of transplantation.

SECTION 4: DEFINITIONS

In general, an organ for transplantation can be obtained from a deceased person ("deceased donor") or a living person ("living donor"). Living donor can be divided into three categories:

- a. Living donor with genetic relationship with the prospective recipient
- b. Living donor with emotional relationship with the prospective recipient
- c. Living donor without any relationship with the prospective recipient

Living donor with genetic relationship with the prospective recipient

The degree of genetic relationship depends on the proportion of genes shared between the two individuals.¹

First degree relationship: a first degree relative shares about half of their genes with the person. This includes the mother, father, daughter, son, full sister (including heterozygous twin/multiple twins) and full brother (including heterozygous twin/multiple twins).

Second degree relationship: a second degree relative shares about one quarter of their genes with the person. This includes the grandmother, grandfather, granddaughter, grandson, aunt, uncle, niece, nephew, half sister and half brother.²

¹ National Genetic Education and Development Centre, National Health Service UK.

² The Health and Social Care Data Dictionary, NHS National Services Scotland UK.

Third degree relationship: a third degree relative shares about one eighth of their genes with the person. This includes great grandmother, great grandfather, great granddaughter, great grandson, great aunt, great uncle, first female cousin, first male cousin, grand niece and grand nephew.

Identical (homozygous) twins share 100% of their genes.

Living donor with emotional relationship with the prospective recipient

These are individuals with personal close relationship with the prospective recipient. For example legal spouse (wife/husband), fiancé, close friend and adopted children.

Living donor without any relationship with the prospective recipient

These are individuals who have no relationship at all with the prospective recipient, either genetic or emotional.

SECTION 5: POLICY¹

- As specified in the National Organ Tissue and Cell Transplantation Policy, organ and tissue shall be procured preferably from deceased donors. However, where appropriate, organs and tissues from living donors may be used.

Degree of Consanguinity	Example	
First degree relative	Mother	Father
	Daughter	Son
	Full sister	Full brother
	(including heterozygous twin/multiple twins)	(including heterozygous twin/multiple twins)
Second degree relative	Grandmother	Grandfather
	Granddaughter	Grandson
	Aunt	Uncle
	Niece	Nephew
	Half sister	Half brother
Third degree relative	Great grandmother	Great grandfather
	Great granddaughter	Great grandson
	Great aunt	Great uncle
	First female cousin	First male cousin
	Grand niece	Grand nephew

Table 1: Summary on Degree of Consanguinity

¹ The revised policy on living organ donation was decided in the National Transplantation Technical Committee Meeting, 14 April 2011.

2. Prior authorisation shall be obtained from the Unrelated Transplant Approval Committee (UTAC) before any organ transplantation involving unrelated living donor can take place. Such organ donation must fulfill the following criteria:
 - a. No available cadaveric donor
 - b. No compatible donor from genetically or emotionally related individuals
3. For the purpose of this guideline, a person is related to the prospective recipient if:
 - a. He/she is an identical (homozygous) twin
 - b. He/she is a first degree relative
 - c. He/she is a second degree relative
 - d. He/she is the legal spouse
4. Transplantation between persons whose relationship extends beyond the above definition shall be evaluated and shall require prior approval from UTAC.
5. It is the responsibility of the clinicians involved in a transplant to verify the status of relationship for every case. If the status of relationship in a particular case is doubtful or difficult to be ascertained, the responsible clinician shall also refer such case to UTAC.
6. ALL unrelated and related living organ transplantations involving non-Malaysian citizens shall receive prior authorisation from UTAC.
7. ALL unrelated and related living organ transplantations shall be reported to the National Transplant Resource Centre on monthly basis. ALL unrelated and related living organ transplantations shall also be reported to the National Transplant Registry.

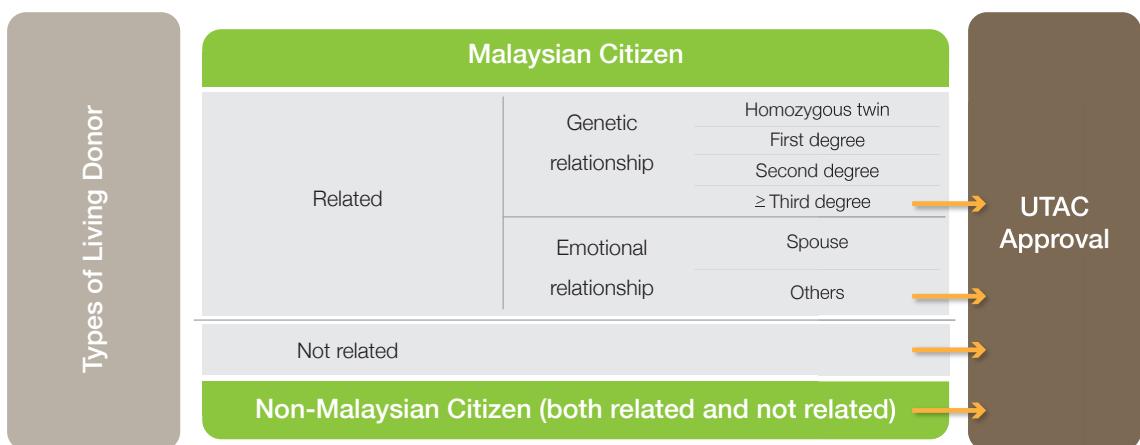


Figure 1: Types of living organ donation that require UTAC Approval

SECTION 6: ASSISTANCE TO A LIVING DONOR

1. As specified in the National Organ, Tissue and Cell Transplantation Policy, the commercialisation of organ, tissue and cell transplantation and any act that may indirectly promote or lead to commercial transaction is prohibited.

2. However, reasonable reimbursement relating to the donation process is permissible but a living organ donor must not make profit from this.
3. In the Ministry of Health's hospitals, a Malaysian citizen who has donated his/her organ is entitled to free first class ward admission for that particular admission for the organ procurement surgery. All hospital charges pertaining to the transplant surgery are also waived.¹

¹ Refer to "Surat Kementerian Kesihatan Malaysia – Pengecualian Bayaran Bil Hospital bagi Pesakit Penderma Organ", 29 December 2003.

4. A public service personnel who has donated his/her organ is entitled to unrecorded leave for not more than 42 days¹ during the peri-operative period.

SECTION 7: GENERAL GUIDELINES

1. In general, a living person wanting to donate organ ("prospective living donor") has to fulfill the following pre-requisites:
 - a. He/she is an adult as defined by law that enables a person to give consent
 - b. He/she is able to understand and assess all the information provided to him/her
 - c. He/she has been informed and understands the potential risks of the surgical procedures, other associated interventions (e.g. investigations) and other long term consequences
 - d. He/she is mentally and physically fit
2. The prospective living donor shall be given enough time to understand all the information provided to him/her and make careful considerations before making a final decision to donate.
3. He/she shall also have the freedom to acquire advice or a second opinion from any clinician or medical institution.
4. A prospective living donor shall undergo an initial evaluation process to ascertain his/her suitability for donating organ.
5. A prospective living donor shall be made aware that he/she has the right to withdraw his/her consent to donate at any time without having to state any reason.
6. The intention of a prospective living donor has to be altruistic. Commercial transaction in exchange for an organ is strictly prohibited. The organ shall not be obtained from the prospective living donor by coercion or any other form of inducement. The prospective living donor and prospective recipient shall be made aware of such prohibitions.

Information to be provided to the prospective living donor

- Alternative treatment for the prospective recipient apart from organ transplantation
- The survival chance of the prospective recipient subsequent to the transplant
- Types of investigations he/she has to undergo and their associated risks and complications
- Possibility that certain condition may be discovered from the investigations that may affect future health and psychosocial status
- Surgical procedure(s) that he/she needs to undergo
- Short term and long term risks of organ donation (e.g. morbidity and mortality rates)
- Success rate of organ transplant in general and of that particular medical institution
- The need of the prospective living donor to undergo long term follow up care
- Prohibition of financial incentive or any other form of inducement
- The rights to withdraw consent at any time even without stating any reason
- Assurance that reason for not proceeding with the donation will remain confidential

¹ Refer to "Surat Pekeliling Ketua Pengarah Kesihatan Bilangan 6 Tahun 2010", 24 February 2010 and "Pekeliling Perkhidmatan JPA Bilangan 3 Tahun 2010", 2 February 2010.

SECTION 8: UNRELATED TRANSPLANT APPROVAL COMMITTEE (UTAC)

This is a committee established by the Director General of Health to evaluate and give advice on appropriateness of all transplant surgeries involving a living donor who is not related to the prospective recipient as specified under Section 5 of this Guideline.

Membership of UTAC

1. The Chairperson and members of the UTAC are appointed by the Director General of Health. They are appointed in their individual capacities.
2. The UTAC shall have a membership of between seven and eleven. Membership shall be made up of doctors and/or non doctors (this may include scientists, allied health personnel or lay persons with knowledge about transplant ethics).
3. The UTAC shall be chaired by a doctor who is not actively involved in the field of transplantation but has sufficient knowledge about transplantation.
4. Members shall be appointed for a period of 3 years.

Terms of Reference of UTAC

1. To evaluate and consider all applications for performing transplantation between individuals who are not related.
2. To propose to the Director General of Health on giving approval for any application.
3. To recommend to the Ministry of Health on policies and guidelines pertaining to the ethics of transplantation involving living donors.

Only 3 to 5 UTAC members will be selected from the group of 7-11 members for a particular application. The appointment of UTAC members for a particular case can be made by the Deputy Director General of Health (Medical).

UTAC is not responsible for judging the clinical appropriateness of any transplant. It is the responsibility of the clinicians concerned to decide on the appropriateness or likelihood of success of a transplant. The approval of UTAC for an unrelated donor transplant does not absolve the clinicians from their normal clinical responsibilities for the donor and the recipient.

Technical Advisors

A group of advisors between 2 and 5 persons may be invited as and when necessary for evaluation of any particular case. The main function of the technical advisor is to give opinion on policy and technical matters when required. Advisors do not have any voting power. Advisors can give opinion in a UTAC meeting when he/she is required and allowed to do so by the Chairperson of UTAC.

Committee Meeting

UTAC shall have at least 1 meeting in a year to review all cases to ensure consistency and to discuss any problems arising. UTAC members can also discuss other relevant matters such as review of policies and procedures, training and other development issues.

Appeals

All appeals will be re considered by UTAC.



SECTION 9: INDEPENDENT DONOR ADVOCATE TEAM (IDAT)

IDAT is a group of at least three donor advocates specifically appointed for the evaluation process of prospective donors. It shall consist of a medical donor advocate, a psychiatrist and a medical social work officer. Donor advocates shall be independent and are not involved in the care of the prospective recipient. This is to minimise conflict of interest. The role of IDAT in general is to carefully evaluate the prospective living donor and provide him/her with necessary information required to make an informed consent. The goal of IDAT is to verify that the act of donation is altruistic, is an autonomous and informed decision.

IDAT shall submit an independent report to the UTAC using Form D, Form E and Form F. Each donor advocate shall evaluate the prospective donor separately.

Donor Advocate: Medical (DA-M)

1. The donor advocate shall be a specialist doctor.
2. The DA-M's role is to ensure that the nature of the transplant procedure has been explained in depth to the potential donor. These should include:
 - a. Donor evaluation procedure
 - b. Surgical procedure
 - c. Recuperative period
 - d. Short and long-term follow-up care
 - e. Alternative donation and transplant procedures
 - f. Potential psychological benefits to the donor
 - g. Transplant centre and surgeon-specific statistics of donor and recipient outcomes
 - h. Confidentiality of donor's information and decision
 - i. Donor's ability to withdraw at any point in the process
 - j. Information on how the transplant centre will attempt to follow up on the health of the donor for life



3. DA-M shall ensure that the prospective donor understands the explanation, including the risks of the operation and any wider implications - for example the potential effects it may have on his work, family life and insurability. Physical risks include:
 - a. Potential for surgical complications including risk of donor death
 - b. Potential for medical complications including long-term complications
 - c. Scars, pain, fatigue, abdominal symptoms
4. The DA-M shall be satisfied that the consent for the removal of the organ was not obtained by coercion or the offer of an inducement.
5. The DA-M shall ensure that the donor has been made aware of the right to change his mind at any time.
6. It is also important for the DA-M to report any difficulties in communicating with the potential donor (e.g. language, literacy level) and how this was overcome. Assistance by an interpreter may be required in certain cases.

Donor Advocate: Psychiatrist (DA-Psy)

1. DA-Psy must make an in-depth evaluation of the potential donor to assess his emotional and psychosocial stability and capability to make an informed decision.
2. DA-Psy shall determine the motivation to donate, presence of anxiety or conflict in decision to donate.
3. DA-Psy shall also ensure that the donor's decision was not made under any duress or coercion.
4. DA-Psy shall identify and help the prospective donor to consider various options in preparing himself/herself for any potential problems such as:
 - a. Potential problems with body image
 - b. Possibility of recipient death
 - c. Possibility of recipient rejection and loss of organ
 - d. Impact on donor's family including opposition from relatives
 - e. Possibility of adjustment disorder post surgery and post surgery depression
 - f. Potential impact of donation on lifestyle
5. DA-Psy may also interview family members of the prospective donor when necessary.

Donor Advocate: Medical Social Work Officer (DA-SW)

1. The DA-SW must obtain a detailed social history of the potential donor and recipient to confirm the nature of their relationship if any.
2. DA-SW shall also assess education background, financial status and social support available in the event of problems.
3. DA-SW shall determine the financial stability of the potential donor so as to preclude financial incentives as a motivating factor for donation.
4. Issues of reimbursement and potential financial hardships should be considered. Potential financial issues include:

- a. Hospitalisation costs and out of pocket expenses
- b. Losses incurred from time off work
- c. Loss of income and possible loss of employment
- d. Potential impact on ability to obtain future employment
- e. Impact on ability to obtain medical and life insurance in the future

SECTION 10: SECRETARIAT OF UTAC

The secretariats for UTAC are the Transplantation Unit, Medical Development Division and also the National Transplant Resource Centre, Hospital Kuala Lumpur. The secretariat shall facilitate application process for UTAC evaluation.

Terms of reference

National Transplant Resource Centre

1. Serve as a resource centre pertaining to policies and procedures on unrelated living organ donation.
2. Guide applicant in preparing relevant documentations including all application forms.
3. Ensure all submitted documentations are complete and in order before proceeding to the next process.
4. Serve as a resource centre for IDAT and UTAC members for a particular case. The secretariat is expected to know relevant and important clinical information about a particular case.
5. Ensure proper filing system for all UTAC applications (as per Appendix) and maintain confidentiality of information.

Transplantation Unit

1. Serve as a resource centre pertaining to policies and procedures on unrelated living organ donation.
2. Guide applicant in preparing relevant documentations including all application forms.

3. Activate UTAC.
4. Ensure all submitted documentations are complete and in order before proceeding to the next process.
5. Serve as a resource centre for UTAC members on a particular case. Secretariat is expected to know relevant and important clinical information about a particular case.
6. Ensure proper filing system for all UTAC applications (as per Appendix) and maintain confidentiality of information.
7. Prepare a Case Summary for every application.

Contact details of secretariats for UTAC:

TRANSPLANTATION UNIT

Medical Development Division
 Ministry of Health Malaysia
 Level 5, Block E1, Complex E
 Federal Government Administrative Centre
 62590 Putrajaya Malaysia

Email : transplantation_unit@moh.gov.my
 Tel. (office) : (603) 88831165
 Tel. (fax) : (603) 88831155

NATIONAL TRANSPLANT RESOURCE CENTRE

Hospital Kuala Lumpur
 Jalan Pahang, 50586 Kuala Lumpur

Email : ntrc@hkl.moh.gov.my
 Tel. (office) : (603) 26942704/2705
 Tel. (fax) : (603) 26156269
 Tel. (toll free) : 1-800-88-9080
 Website : www.agiftoflife.gov.my

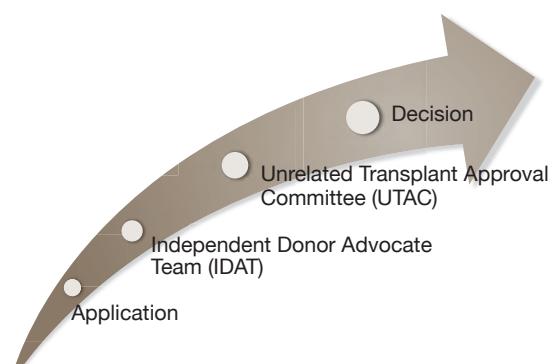


Figure 2: The 4 Basic Steps in Applying for UTAC Evaluation

SECTION 11: PROCEDURES OF APPLICATION

Procedures for applicants

1. Applicant shall be the doctor responsible for the prospective donor or the doctor responsible for the prospective recipient. The doctor responsible for the prospective donor and the doctor responsible for the prospective recipient shall be different individuals.
2. Doctor responsible for the prospective recipient shall prepare a **Medical Report** certifying medical suitability of the recipient to undergo transplantation and that transplantation is the medical treatment of choice. Relevant investigations reports shall be attached with the Medical Report.
3. Doctor responsible for the prospective donor shall coordinate evaluation process for the prospective donor and prepare a **Medical Report** certifying medical suitability of the prospective donor to undergo surgery. Only basic and preliminary investigations to ascertain fitness and suitability are required at this stage. Invasive investigations on the prospective donor need not be carried out. Relevant investigations reports shall be attached with the Medical Report.

Responsibilities of the doctor submitting the application

- Prospective donor shall be given appropriate and adequate information especially with regards to the risk of the surgical procedures. Failure to provide such information can be regarded as an attempt for an inducement. Copies of the leaflets on "Living Organ Donation" should be given to the prospective donor and the prospective recipient.
- Commercial transaction in exchange for an organ is strictly prohibited. Organ shall not be obtained from the prospective donor by coercion or any other form of inducement. Prospective donor and prospective recipient shall be made aware of such prohibition.
- The doctor responsible for the prospective donor must bear witness to the declaration by the prospective donor stating clearly that (i) He/she is in full control of his mental and physical faculties (ii) He/she has made the decision independently and without any duress, coercion, inducement or promise (iii) He/she has understood and accepted the risks and possible outcomes of the operation.
- The applicants must declare that they have not been involved with any inducement or commercial dealings in the proposed transplants.
- The doctor responsible shall also ensure confidentiality is preserved.
- If there is any difficulty in communicating with the donor or recipient due to language or literacy level, a suitable interpreter shall be used. The interpreter should have no personal involvement to either party or the transplant.



4. Applicants shall fill in Form A, Form B and Form C.

Form	Description	Signatories
Form A	General information <ul style="list-style-type: none"> This form shall contain general information such as type of surgical procedures, name of medical institution, name of prospective donor and recipient, name of panel doctors responsible for the case. Applicant shall also describe why living related donor is not available and donor-recipient relationship, if any. 	<ul style="list-style-type: none"> Doctor responsible for the prospective donor. Doctor responsible for the prospective recipient. Doctor performing the procurement surgery. Doctor performing the transplantation surgery.
Form B	Application By The Prospective Living Donor <ul style="list-style-type: none"> This form shall contain more detail information about the prospective donor, declaration of the prospective donor, declaration of the doctor responsible for the prospective donor and declaration of the interpreter. Declaration includes consent by the prospective living donor to donate organ to the prospective recipient. 	<ul style="list-style-type: none"> Prospective donor. Doctor responsible for the prospective donor. Interpreter (if applicable).
Form C	Application By The Prospective Recipient <ul style="list-style-type: none"> This form shall contain more detail information about the prospective recipient, declaration of the prospective recipient, declaration of the doctor responsible for the prospective donor and declaration of the interpreter. Declaration includes consent by the prospective recipient to receive organ from the prospective donor. 	<ul style="list-style-type: none"> Prospective recipient. Doctor responsible for the prospective recipient. Interpreter (if applicable).

Table 2: Forms to be filled in by the applicant

5. Application forms together with other relevant documents (please refer to Checklist B) shall be submitted to the National Transplant Resource Centre (NTRC), preferably by hand.
6. NTRC will ensure that all relevant documents are in order and complete before proceeding with the process. Incomplete documentations will not be accepted.

Important notes for the applicants

- UTAC will not be responsible for any consequences of the surgical procedures. It is the responsibility of the doctor submitting the application to take necessary measures to ensure the smooth running of the procedure. Similarly, medico-legal and safety issues of the prospective donor and prospective recipient are the responsibilities of the doctor and also the medical institution. Ministry of Health Malaysia shall also not be responsible for such issues.
- Doctor responsible for the application and also the medical institution shall submit a report pertaining to the surgical procedure including outcome for both donor and recipient to the Ministry of Health within one month after the procedure took place.
- The approval of UTAC is only valid if at the time of transplant the conditions remain the same as when reported to UTAC. The doctor responsible must satisfy himself/herself, before operating on the donor that there has been no material change of circumstances. If there has been a change, the applicants must reapply to the UTAC.

Procedures for Secretariat, IDAT, Advisors and Members of UTAC

7. NTRC will inform the Transplantation Unit, Medical Development Division about the application.
8. Transplantation Unit will activate UTAC. Members of UTAC (3 to 5 members), Advisors of UTAC and members of Independent Donor Advocates Team (IDAT) will be identified and officially appointed. Transplantation Unit shall ensure letters of appointment and other necessary official documentations are in order (please refer to Checklist A). Members, Advisors and Secretariats of UTAC shall sign a Declaration of Conflict of Interest and Confidentiality (as per Appendix) if they agree to the Appointment.
9. NTRC will arrange the evaluation session of prospective donor with IDAT. If necessary, family members of the prospective donor can also be called to the evaluation session. The prospective donor and the family members can be evaluated together and/or separately.
10. Copies of all documentations as in Checklist B shall be made available to IDAT for their reference.
11. IDAT will fill in and submit Form D, Form E and Form F to NTRC subsequent to the evaluation process. If applicable, IDAT shall also submit genogram together with other relevant documentations.
12. IDAT shall be given ample time to make a fair and thorough evaluation.
13. IDAT shall also be given reasonable period of time to prepare the independent report as per Form D, Form E and Form F.
14. NTRC will ensure that all relevant documents are in order and complete before proceeding with the next process (please refer to Checklist A).
15. NTRC will submit completed documents to the Transplantation Unit.

Form	Description	Signatories
Form D	Donor Evaluation: Report By Donor Advocate (Medical) <ul style="list-style-type: none"> • Risk benefit assessment 	• Donor Advocate (Medical)
Form E	Donor Evaluation: Report By Donor Advocate (Psychiatrist) <ul style="list-style-type: none"> • Psychiatric evaluation 	• Donor Advocate (Psychiatrist)
Form D	Donor Evaluation: Report By Donor Advocate (Medical Social Work Officer) <ul style="list-style-type: none"> • Psycho-social evaluation 	• Donor Advocate (Medical Social Work Officer)

Table 3: Forms to be filled in by Members of the Independent Donor Advocates Team (IDAT)

16. Transplantation Unit will ensure that all relevant documents are in order and complete before proceeding with the next process (please refer to Checklist A). Transplantation Unit may request additional and relevant documents either from the Applicants or IDAT if necessary.
17. Transplantation Unit will arrange a meeting of the UTAC members. Copies of all documentations as in Checklist A shall be made available to UTAC members for their reference before the meeting. UTAC members shall be given ample time to go through the documents before the meeting.
18. UTAC members are expected to reach a decision within 5 working days after the meeting. A decision can be made on the same day of the meeting. UTAC members may request additional and relevant documents either from the Applicants or IDAT if necessary. A decision is deferred until further information and documentations are available. UTAC members can be conferred through telephone or email to reach a decision.
19. Once a decision is made, the Chairperson of UTAC will officially inform the Director General of Health about the decision. The Chairperson will write directly to the Director General of Health.
20. The Director General of Health will officially inform the applicants about the final decision.
21. Transplantation Unit is expected to prepare a Case Summary according to the format as in Appendix. Case Summary and all other documents shall be kept as confidential and only privileged persons have the rights to review those documents.

Special Circumstances

22. If the appointed UTAC members are undecided about a case, an additional 2 members shall be identified and appointed. If the appointed UTAC members remain undecided, all UTAC members will have to convene a meeting to solve the case.
23. If the applicant wishes to appeal a UTAC decision, the applicant shall write to the Director General of Health. An additional 2 members shall be identified and appointed to consider the appeal.



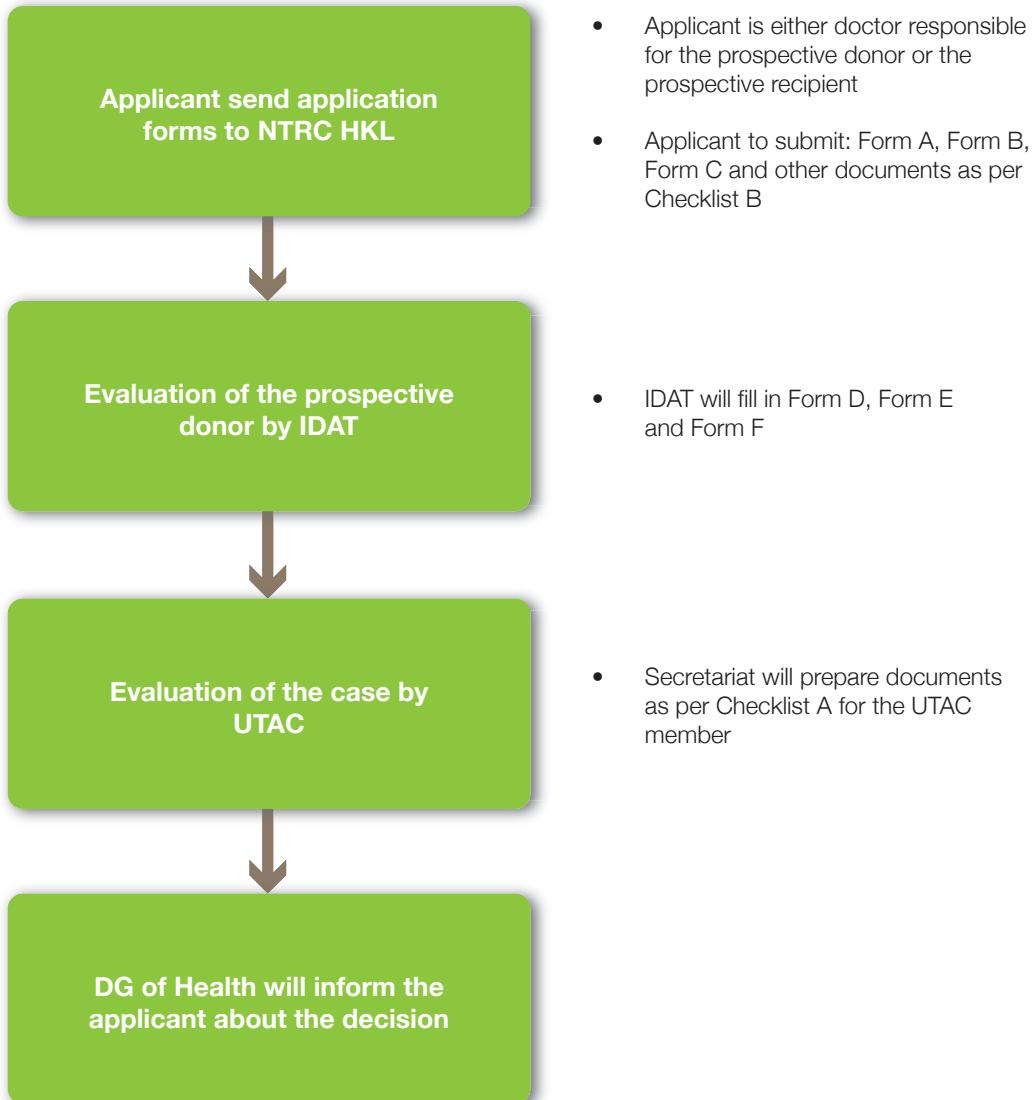


Figure 3: Flowchart of Process for UTAC Application

BIBLIOGRAPHY

Constitution of the World Health Organization. New York: International Health Conference, 1946.

WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation: World Health Organization, May 2010.

The Declaration of Istanbul on Organ Trafficking and Transplant Tourism: the Transplantation Society and International Society of Nephrology, May 2008.

Strong RW. Living Donor Liver Transplantation: an Overview. *Journal of Hepatobiliary Pancreatic Surgery* 2005;13:370-77.

Matas AJ, Bartlett ST, Leichtman AB, Delmonico FL. Morbidity and Mortality After Living Kidney Donation 1999–2001: Survey of United States Transplant Centers. *American Journal of Transplantation* 2003;3:830-34.

National Organ, Tissue and Cell Transplantation Policy. Putrajaya: Medical Development Division, Ministry of Health, 2007.

Rudow DL. The Living Donor Advocate: a Team Approach to Educate, Evaluate, and Manage Donors Across the Continuum. *Progress in Transplantation* March 2009;19(1):64-70.

United Kingdom Guidelines For Living Donor Kidney Transplantation: the British Transplantation Society and the Renal Association, January 2000.

Ahmed N, Ahmed K, Khan MS, Calder F, Mamode N, Taylor J, et al. Living-unrelated Donor Renal Transplantation: an Alternative to Living-related Donor Transplantation? *Annum Royal College of Surgeon England* 2008;90:247-50.

Delmonico FL, Davis CL. Living-Donor Kidney Transplantation: A Review of the Current Practices for the Live Donor. *American Society of Nephrology* 2005;16:2098-110.

Guidelines of Malaysian Medical Council: Organ Transplantation: Malaysian Medical Council, 14 November 2006.

Appendix



Appendix 1

Checklist A (Secretariat)

**APPLICATION FOR EVALUATION AND APPROVAL OF THE UNRELATED TRANSPLANT APPROVAL
COMMITTEE (UTAC), MINISTRY OF HEALTH MALAYSIA**

Checklist for the secretariat*

- | | |
|--------------------------|---|
| <input type="checkbox"/> | CHECKLIST A (Secretariat) |
| <input type="checkbox"/> | CHECKLIST B (Applicants) |
| <input type="checkbox"/> | FORM A (UTAC): Application for Unrelated Living Transplant |
| <input type="checkbox"/> | FORM B (UTAC): Declaration by the Prospective Living Donor |
| <input type="checkbox"/> | FORM C (UTAC): Declaration by the Prospective Recipient |
| <input type="checkbox"/> | FORM D (UTAC): Donor Evaluation: Report By Donor Advocate (Medical) |
| <input type="checkbox"/> | FORM E (UTAC): Donor Evaluation: Report By Donor Advocate (Psychiatrist) |
| <input type="checkbox"/> | FORM F (UTAC): Donor Evaluation: Report By Donor Advocate (Medical Social Work Officer) |
| <input type="checkbox"/> | A copy of prospective donor IC/passport |
| <input type="checkbox"/> | A copy of prospective recipient IC/passport |
| <input type="checkbox"/> | Medical report of prospective donor (with relevant preliminary investigation reports) |
| <input type="checkbox"/> | Medical report of prospective recipient (with relevant preliminary investigation reports) |
| <input type="checkbox"/> | Pay slip of the prospective donor (or any other form of documentation) |
| <input type="checkbox"/> | Certified true copy of marriage certificate (if applicable) |
| <input type="checkbox"/> | Genogram – provided by donor advocate (if applicable) |

(for office use only)

Completed

Not completed

Comments

.....

.....

.....

(signature of secretariat)

Name:

Date:

* Please tick if applicable

CHECKLIST A (SECRETARIAT)

Please list down additional documentations:

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

(for office use only)

Completed

Not completed

Comments

.....

.....

.....

(signature of secretariat)

Name:

Date:

List of other official documents*

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Holding reply letter to the applicant |
| <input type="checkbox"/> | Letter of appointment of Members of Unrelated Transplant Approval Committee (UTAC) |
| <input type="checkbox"/> | Letter of appointment of Members of Independent Donor Advocates Team (IDAT) |
| <input type="checkbox"/> | Letter of appointment of Advisors of UTAC |
| <input type="checkbox"/> | Call letter for evaluation session of prospective donor by IDAT |
| <input type="checkbox"/> | Call letter for UTAC meeting |
| <input type="checkbox"/> | Declaration of Conflict of Interest and Confidentiality (UTAC Members) |
| <input type="checkbox"/> | Declaration of Conflict of Interest and Confidentiality (UTAC Advisors) |
| <input type="checkbox"/> | Declaration of Conflict of Interest and Confidentiality (UTAC Secretariats) |
| <input type="checkbox"/> | Declaration of Conflict of Interest and Confidentiality (IDAT Members) |
| <input type="checkbox"/> | Letter by Chairperson of UTAC to the Director General of Health about UTAC decision |
| <input type="checkbox"/> | Letter by the Director General of Health to the applicant about the final decision |
| <input type="checkbox"/> | Case summary |

* Please tick if applicable

Appendix 2

Checklist B (Applicants)

**APPLICATION FOR EVALUATION AND APPROVAL OF THE UNRELATED TRANSPLANT APPROVAL
COMMITTEE (UTAC), MINISTRY OF HEALTH MALAYSIA**

Checklist for the applicants*

- | | |
|--------------------------|---|
| <input type="checkbox"/> | CHECKLIST B (Applicants) |
| <input type="checkbox"/> | FORM A (UTAC): Application for Unrelated Living Transplant |
| <input type="checkbox"/> | FORM B (UTAC): Declaration by the Prospective Living Donor |
| <input type="checkbox"/> | FORM C (UTAC): Declaration by the Prospective Recipient |
| <input type="checkbox"/> | A copy of prospective donor IC/passport |
| <input type="checkbox"/> | A copy of prospective recipient IC/passport |
| <input type="checkbox"/> | Medical report of prospective donor (with relevant preliminary investigation reports) |
| <input type="checkbox"/> | Medical report of prospective recipient (with relevant preliminary investigation reports) |
| <input type="checkbox"/> | Pay slip of the prospective donor (or any other form of documentation) |
| <input type="checkbox"/> | Certified true copy of marriage certificate (if applicable) |

Comments by applicants (if any) (signature of applicant) Name: Date:	(for office use only) <div style="text-align: center;"> <input type="checkbox"/> Completed <input type="checkbox"/> Not completed </div> Comments (signature of secretariat) Name: Date:
--	---

* Please tick if applicable

CHECKLIST B (APPLICANTS)

Please list down additional documentations:

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

<p>Comments by applicants (if any)</p> <p>.....</p> <p>(signature of applicant)</p> <p>Name: Date:</p>	<p>(for office use only)</p> <p><input type="checkbox"/> Completed <input type="checkbox"/> Not completed</p> <p>Comments</p> <p>.....</p> <p>(signature of secretariat)</p> <p>Name: Date:</p>
--	---

Appendix 3
Form A (UTAC):
Application for Living Unrelated Transplant



APPLICATION FOR LIVING UNRELATED TRANSPLANT

This form is to be filled in by a panel of doctors responsible for this application.

Case no	:
Date of submission	:

Section 1: Information about the surgical procedure

Organ to be transplanted :

Name of surgical procedure :

.....
.....

Section 2: Information about the institution

Name of hospital :

Address :

.....
.....

Telephone (O) :

Fax :

Website :

Email :

Section 3: Information about panel doctors**Doctor responsible for the prospective recipient**

Name :

IC no. :

MMC no. :

Designation :

Professional qualifications :

Address :
.....
.....

Telephone (office and hp) :

Fax :

Email :

Doctor responsible for the prospective donor*

Name :

IC no. :

MMC no. :

Designation :

Professional qualifications :

Address :
.....
.....

Telephone (office and hp) :

Fax :

Email :

* Doctor responsible for the donor and doctor responsible for the recipient shall be different

Doctor who will be performing the organ procurement surgery

Name :

IC no. :

MMC no. :

Designation :

Professional qualifications :

Address :

.....

.....

Telephone (office and hp) :

Fax :

Email :

Doctor who will be performing the organ transplantation surgery

Name :

IC no. :

MMC no. :

Designation :

Professional qualifications :

Address :

.....

.....

Telephone (office and hp) :

Fax :

Email :

Section 4: Information about prospective recipient and donor**Prospective recipient**

Name :

IC no. :

Address :

.....

.....

Telephone (office and hp) :

Fax :

Email :

Prospective donor

Name :

IC no. :

Address :

.....

.....

Telephone (office and hp) :

Fax :

Email :

FORM A (UTAC)

Please state reasons why living donor from genetically related individuals is not available:

.....
.....
.....
.....
.....
.....
.....
.....

Please describe relationship between prospective donor and prospective recipient (if any):

.....
.....
.....
.....
.....
.....
.....
.....

Section 5: Declaration of panel doctors

We, hereby submit an application for evaluation and approval to perform..... transplantation between individuals who are not related. We declare that there is no coercion to the prospective living donor to consent to the donation and there is no monetary payment or other reward of monetary value offered to the prospective living donor in exchange for the organ. We also certified all information provided is true.

(signature)

(signature)

Name : Name :

IC : IC :

MMC no. : MMC no. :

Designation : Designation :

Institution : Institution :

(signature)

(signature)

Name : Name :

IC : IC :

MMC no. : MMC no. :

Designation : Designation :

Institution : Institution :

Appendix 4
Form B (UTAC):
Declaration by the Prospective Living Donor



DECLARATION BY THE PROSPECTIVE LIVING DONOR

This form is to be filled in by the prospective living donor and to be witnessed by the doctor responsible for him/her. Doctor responsible for the donor and doctor responsible for the recipient shall be different individuals.

This is not a consent form for surgical operation. If this application is approved, a separate surgical consent form has to be filled in and signed by the prospective donor.

Case no	:
Date of submission	:

Section 1: Information for the prospective donor

1. A transplant using an organ taken from a living donor who is not closely related to the recipient is only permitted after approval by the Unrelated Transplant Approval Committee (UTAC). UTAC must be satisfied that all requirements stated in the National Organ, Tissue and Cell Transplantation Policy have been met before the transplant can take place. The decision on whether you are medically fit and suitable as a live organ donor is a matter for the doctor(s) concerned. The doctors are required to explain to you what is involved in becoming an organ donor, what are the risks and chances of a successful transplant and what the after effects are likely to be.
2. It is for you to decide whether you wish to go ahead with the procedure. You are entitled to change your mind and decide not to allow your organ to be removed at any time before the start of the operation.
3. The National Organ, Tissue and Cell Transplantation Policy prohibits the receipt of any payment or any other benefit for providing an organ for a transplant. No-one, including the recipient, is permitted to put pressure on you to donate your organ by any kind of coercion or threat against you or anyone else (for example your family or friends).
4. "Other benefit" would include such things as any promise of promotion, better work, better housing for you or a member of your family. You may be reimbursed for expenses or loss of earnings which are reasonably attributable to and directly result from you donating an organ - but you must not make a profit from this.
5. If UTAC can be satisfied that the requirements have been met, you, as a prospective donor, are asked to sign a declaration. Before you sign make sure that your doctor has given you a copy of the leaflet "Living Organ Donation", that you have had as much time as you want to read it, and think about it and that your questions have been answered. Your doctor should be present when you sign the form.

Section 2: Personal information

Picture of the
prospective living
donor

Name	:
IC no./passport	:
Address	:
Telephone (home)	:
Telephone (hand phone)	:
Email	:
Race	:
Religion	:
Sex	:
Nationality	:
Date of birth	:
Place of birth	:
Level of education	:
Marital status	:
Occupation	:
Monthly salary	:

Section 3: Declaration of the prospective living donor

I, hereby express my wish to donate my(Please specify organ) to(Name/IC/passport of prospective recipient).

I declare that, I have read Section 1 of this form /I have had Section 1 of this form translated to me and confirm that:-

1. I understand the nature of the requirements referred to in that section.
2. No payment of money or of money's worth has been made to me or will be made to me or to any other person as a result of this donation.
3. I have not been coerced in any way to give my consent to the removal of that organ.
4. I have not been offered any form of inducement and I am not aware that any other person has been offered any form of inducement for me to give my consent for the removal of that organ.
5. I have been given a full explanation of the nature of the medical procedure involved and of the risks involved for me in the removal of my(Please specify organ). That explanation was given by (State name of registered medical practitioner).
6. I understand the nature of that medical procedure and of the risks to me as explained by that practitioner.
7. I consent to the removal of my..... (Please specify organ).
8. I understand that I may withdraw my consent to the removal of that organ at any time before the operation takes place.
9. I understand that the information I have given in this form will be used only in connection with the requirements in respect of live organ donation/transplantation and that it may be stored on a computer system maintained for UTAC's purposes and it will kept confidential.
10. I have/have not* required the assistance of an interpreter.
11. I have received and read a copy of the leaflet "Living Organ Donation".

.....
(signature of prospective donor)

Name :

IC :

Date :

* Delete whichever not applicable

Section 4: Declaration of the doctor responsible for the prospective donor

I hereby confirm that:

1. I am the clinician responsible for the prospective donor who has signed Section 3 of this form.
2. The nature of the medical procedure and the risks involved in the removal of his/her*.....(Please specify organ) were explained by me/by*.....(Name/IC of other registered medical practitioner).
3. Aid of the interpreter was not required/ required (as named in Section 5)*.
4. So far as I am aware the declarations he/she* has made are true and I witnessed his/her signature to Section 3.
5. I have provided the prospective donor with a copy of the leaflet "Living Organ Donation".

.....
(signature of the doctor responsible for the
prospective donor)

Name :

IC :

MMC no. :

Designation :

Institution :

Section 5: Declaration of the interpreter (if applicable)

I declare that:

1. I have interpreted this document to (*name of the prospective donor*) in (*specify language*).
2. I am not known either to the prospective donor or the prospective recipient named in Section 2 and Section 3 of this form before being asked to interpret on this matter.
3. I have translated all the information in Section 1, Section 2 and Section 3 of this form to the prospective donor and I believe that he/she* understood that information before signing Section 3 of this form.

.....
(signature of the interpreter)

Name :

IC :

Designation :

Address :

.....

Tel. no. (home) :

Tel. no (hp) :

Email :

Date :

* Delete whichever not applicable

Appendix 5
Form C (UTAC):
Declaration by the Prospective Recipient



DECLARATION BY THE PROSPECTIVE RECIPIENT

This form is to be filled in by the prospective recipient and to be witnessed by the doctor responsible for him/her. Doctor responsible for the donor and doctor responsible for the recipient shall be different individuals.

This is not a consent form for surgery. If this application is approved, a separate surgical consent form has to be filled in and signed by the prospective recipient.

Case no	:
Date of submission	:

Section 1: Information for the prospective recipient

1. A transplant using an organ taken from a living donor who is not closely related to the recipient is permitted only after approval by the Unrelated Transplant Approval Committee (UTAC) in certain circumstances. UTAC must be satisfied that all requirements have been met before the transplant can take place. The decision on whether the unrelated person is medically fit and suitable as a live organ donor is a matter for the doctor(s) concerned. The doctors are required to explain to that person what is involved in becoming a live organ donor, what the risks and chances of a successful transplant are and what the after effects are likely to be.
2. It is for the prospective donor to decide whether he/she wishes to go ahead with the procedure. He/she is entitled to change his/her mind and decide not to allow his/her organ to be removed at any time before the start of the operation.
3. It is prohibited by the National Organ, Tissue and Cell Transplantation Policy to offer, give or receive any payment or other benefit for providing an organ for a transplant. No-one, including yourself, is permitted to try to influence a person to donate an organ by any kind of coercion or threat against the prospective donor or anyone else (for example his/her family or friends).
4. "Payment or other benefit" would include such things as any promise of promotion, better work, better housing for the donor or payment or benefit to any member of the donor's family. The donor may be reimbursed for expenses and loss of earnings which are reasonably attributable to and directly result from him/her donating an organ - but he/she must not make a profit from this.
5. In order that UTAC can be satisfied that the requirements have been met, each prospective recipient is asked to sign the declaration overleaf. Before you sign make sure that your doctor has given you a copy of the leaflet "Living Organ Donation" that you have had as much time as you want to read it and think about it, and that your questions have been answered. Your doctor should be present when you sign the form.

Section 2: Personal information

Picture of the
prospective living
donor

Name :

IC no./passport :

Address :

Tel. no. (home) :

Tel. no (hand phone) :

Email :

Race :

Religion :

Sex :

Nationality :

Date of birth :

Place of birth :

Marital status :

Occupation :

Section 3: Declaration of the prospective recipient

I, hereby agree to receive(Please specify organ) from a living person named (Name/IC/Passport of prospective donor).

I have read Section 1 of this form /I have had Section 1 of this form translated to me and declare that:-

1. No payment of money or kind as referred to in section 1 of that act has been made by me or will be made by me or by any other person to the prospective donor.
2. I have not coerced the prospective donor in any way and I am not aware that any other person has coerced the prospective donor, to give his/her* consent for the removal of the organ.
3. I have not offered any form of inducement and I am not aware that any other person has offered any form of inducement, to the prospective donor, to give his/her* consent for the removal of the organ.
4. I understand that the information I have given on this form will be kept confidential and will be used only in connection with satisfying the requirements in respect of live organ donation/transplantation and that it may be stored on a computer system maintained for UTAC's purposes.
5. I have/have not* required the assistance of an interpreter.
6. I have received and read a copy of the leaflet "Living Organ Donation".

.....
(signature of prospective recipient)

Name :

IC :

Date :

* Delete whichever not applicable

Section 4: Declaration of the doctor responsible for the prospective recipient

I hereby confirm that:

1. I am the doctor responsible for the prospective recipient (or parent of recipient) who has signed Section 3 of this form.
2. So far as I am aware the declarations he/she* has made are true and I witnessed his signature to that in Section 3.
4. The nature of the medical procedure and the risks involved in the removal of his/her* (*Please specify organ*) were explained by me/ by*..... (*Name/IC of other registered medical practitioner*).
5. Aid of the interpreter was not required/ required (as named in Section 5)*.

.....
(signature of the doctor responsible for the
prospective recipient)

Name :

IC :

MMC no. :

Designation :

Institution :

Section 5: Declaration of the interpreter (if applicable)

I declare that:

1. I have interpreted this document to (*name of the prospective donor*) in (*specify language*).
2. I was not known either to the prospective donor or the prospective recipient named in Section 2 and Section 3 of this form before being asked to interpret on this matter.
3. I have translated all the information in Section 1, Section 2 and Section 3 of this form to the prospective recipient and I believe that he/she* understands that information and that he/she* has freely consented to signing Section 3 of this form.

.....
(signature of the interpreter)

Name :

IC :

Designation :

Address :

.....

Tel. no. (home) :

Tel. no (hp) :

Email :

Date :

* Delete whichever not applicable

Appendix 6

Form D (UTAC): Donor Evaluation:
Report by Donor Advocate (Medical)



DONOR EVALUATION: REPORT BY DONOR ADVOCATE (MEDICAL)

*This form is to be filled in by an appointed donor advocate evaluating prospective living donor under the
Unrelated Transplant Approval Committee (UTAC),
Ministry of Health Malaysia.*

Case no	:
Date of evaluation	:

Section 1: Personal Information

Name :

Race :

Religion :

Sex :

Level of education :

Marital status :

Occupation :

Section 2: Donor Advocate's Note

Has the doctor responsible for the donor given the donor an explanation of:

	YES	NO
1. Donor evaluation procedure	<input type="checkbox"/>	<input type="checkbox"/>
2. Surgical procedure	<input type="checkbox"/>	<input type="checkbox"/>
3. Recuperative period (4-12 weeks)	<input type="checkbox"/>	<input type="checkbox"/>
4. Short and long-term follow-up care	<input type="checkbox"/>	<input type="checkbox"/>
5. Alternative treatment	<input type="checkbox"/>	<input type="checkbox"/>
6. Transplant centre and surgeon-specific statistics of donor and recipient outcomes	<input type="checkbox"/>	<input type="checkbox"/>
7. Confidentiality of donor's information and decision	<input type="checkbox"/>	<input type="checkbox"/>
8. Donor's ability to withdraw at any point in the process	<input type="checkbox"/>	<input type="checkbox"/>
9. Information on how the transplant centre will attempt follow the health of the donor for life	<input type="checkbox"/>	<input type="checkbox"/>

Potential risk:**YES****NO**

10. The risk of death (estimated 3.1 in 10,000 for kidneys and 1 in 200 for right lobe liver and 1 in 1,000 for left lobe liver)

11. Idiosyncratic reaction to anaesthetic or other drugs

12. General complications of major abdominal surgery

- a. DVT, pulmonary embolism
- b. Intra-abdominal bleeding and abscess
- c. Wound haematoma, infection, herniation, scar
- d. Pneumonia and atelectasis
- e. Urinary retention and UTI
- f. Possible need for blood transfusion
- g. Risk of small bowel adhesion (in transperitoneal surgery)
- h. Jaundice

13. Possibility of prolong hospitalisation and additional surgery/interventional procedures

14. Possibility of short and long term wound pain

15. Long term medical complications e.g. possibility of small increase in BP and incidence of proteinuria

16. Possibility of psycho-social symptoms

17. Possible effects of the donation on his work, family life and insurability

Section 3: Other clinical notes

Other clinical notes

Section 4: Conclusion

I am satisfied/not satisfied* that the donor understands the nature of the surgical procedure and the risks as explained by the doctor, and consents to the removal of the organ.

I am satisfied/not satisfied* that the donor's consent for the removal of the organ was not obtained by coercion or the offer of an inducement.

I am satisfied/not satisfied* that the donor understands that she/he is entitled to withdraw consent at any time.

If the answer to any of the above was “not satisfied”, then the Donor Advocate should make clear the reasons for his doubts or dissatisfaction:

(signature of medical donor advocate)

Name :

|C |

MMC no.:

Designation :

Institution :

* Delete whichever not applicable

Appendix 7

Form E (UTAC): Donor Evaluation:
Report by Donor Advocate (Psychiatrist)



**DONOR EVALUATION:
REPORT BY DONOR ADVOCATE (PSYCHIATRIST)**

*This form is to be filled in by an appointed psychiatrist evaluating prospective living donor
under the Unrelated Transplant Approval Committee (UTAC),
Ministry of Health Malaysia.*

Case no	:
Date of evaluation	:

Section 1: Personal information

Name :

Race :

Religion :

Gender :

Nationality :

Age :

Level of education :

Marital status :

Occupation :

Section 2: Relationship to prospective recipient Spouse Family; please indicate : Not related; please indicate :

Status of living:

 Living together Living separately

Status of connectivity:

 Recipient dependent on donor Recipient not dependent on donor Donor dependent on recipient Donor not dependent on recipient

Section 3: Assessment findings

A. Mental state

- knowledge
 - source of information
 - coercion
 - expectation
 - donor's family background
 - prior understanding between prospective donor and prospective recipient

ANSWER

Satisfactory

Page 1

Not satisfactory

Please give comments:

B. Donor's decision process to donate

- understanding about procedure
 - understanding about complications
 - understanding about post-operative care

ANSWER

Satisfactory

ANSWER

Not satisfactory

Please give comments:

C. Presence of prospective factor (or factors) that may lead to future psychosocial problem

- substance /alcohol abuse
 - personality disorder
 - social support
 - legal proceeding
 - financial background
 - mental incapacity

Page 1

Satisfactory

Page 1

Not satisfactory

Please give comments:

D. Mental state

- current active psychopathology
 - past psychiatric history
 - current mental state

ANSWER

Satisfactory

A large, empty rectangular box with a thin black border, occupying most of the page below the title.

Not satisfactory

Please give comments:

Section 3: Other clinical notes

Other clinical notes

Section 4: Conclusion

I am satisfied/not satisfied* the donor is emotionally and psychosocially stable and capable of making an informed decision.

Other comments (if relevant):

(signature of the psychiatrist)

Name :

IC :

MMC no. :

Designation :

Institution :

* Delete whichever not applicable

Appendix 8

Form F (UTAC): Donor Evaluation:
Report by Donor Advocate (Medical Social Work Officer)



**DONOR EVALUATION:
REPORT BY DONOR ADVOCATE (MEDICAL SOCIAL WORK OFFICER)**

This form is to be filled in by an appointed medical social work officer evaluating prospective living donor under the Unrelated Transplant Approval Committee (UTAC), Ministry of Health Malaysia.

Case no	:
Date of evaluation	:

Section 1: Personal Information

Name :

IC no. :

Address :

Tel. no. (home) :

Tel. no (hand phone) :

Email :

Race :

Religion :

Sex :

Nationality :

Date of birth :

Place of birth :

Level of education :

Marital status :

Occupation :

Other information * :

Section 2: Relationship to prospective recipient

Spouse

Family; please indicate :

Not related; please indicate :

* Handicap, past medical history, criminal records, drug abuse

Section 3: Family details

No.	Name	Age	Sex/marital status	Relationship	Occupation	Income	Other remarks

No.	Name	Age	Sex/marital status	Relationship	Occupation	Income	Other remarks

Section 4: Economic background**Monthly income**

Prospective donor (or parents to prospective donor)

Salary	: RM	
Other source of income	: RM	Please indicate:
	: RM	Please indicate:
	: RM	Please indicate:
Total monthly income	: RM	
Total yearly income	: RM	

Spouse

Salary	: RM	
Other source of income	: RM	Please indicate:
	: RM	Please indicate:
	: RM	Please indicate:
Total monthly income	: RM	
Total yearly income	: RM	

Monthly expenses

House (rental/installment) : RM	
Car (installment) : RM	
Utility : RM	
Children schooling : RM	
House whole : RM	
Other expenses : RM	Please indicate:
: RM	Please indicate:
: RM	Please indicate:
: RM	Please indicate:
: RM	Please indicate:
: RM	Please indicate:
Total monthly expenses : RM	

Net monthly income

Total monthly income : RM	
Total monthly expenses : RM	
Balance : RM	

Other assets

Total current saving : RM	
Monthly saving : RM	

Others

Kumpulan Wang Simpanan Pekerja (KWSP) : RM	
PERKESO : RM	
Health insurance : RM	
Others : RM	

FORM F (UTAC)

Other comments about economic background (if relevant):

Section 5: Prospective Donor's House**a.Status**

- Owned by the prospective donor
- Rental house
- Rental room
- Employers (e.g. quarters)
- Family's house
- Government assistance (e.g. Projek Perumahan Rakyat Termiskin)
- Others (e.g. staying with friends); please indicate:

b.Type of house

- Wooden house
- Concrete and wooden house
- Concrete house
- Flat/condominium
- Terrace house (middle cost)
- Semi-detached
- Bungalow

c.Household facilities

- | | |
|---|--|
| <input type="checkbox"/> Telephone | <input type="checkbox"/> Hand phone |
| <input type="checkbox"/> Refrigerator | <input type="checkbox"/> TV |
| <input type="checkbox"/> Cooker (gas, electrical, wood) | <input type="checkbox"/> Electricity |
| <input type="checkbox"/> Tap water | <input type="checkbox"/> Others: |

FORM F (UTAC)

- d. Additional information about donor's house based on home visit (surrounding area, pollution level, sanitary and others):

Section 6: Psycho-social assessment

a. Family and donor him/herself agree to this donation?

Yes

No

If NO, please comment further:

.....
.....
.....
.....
.....
.....
.....

b. The donor has the ability to bear the cost before, during and after donation?

Yes

No

Please give comments:

.....
.....
.....
.....
.....
.....

FORM F (UTAC)

c. Family members support this donation?

Yes

No

Please give comments (Who support and who oppose? Reasons etc.):

.....
.....
.....
.....
.....
.....
.....
.....

d. Please describe potential economic implications as a result to this donation:

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

e. Please describe potential social implications as a result to this donation:

.....
.....
.....
.....
.....
.....

f. Please describe factor (or factors) that influences the decision to donate:

.....
.....
.....
.....
.....
.....

g. Please describe prospective donor's expectations from this donation:

.....
.....
.....
.....
.....
.....

Section 6: Other clinical notes

Other clinical notes

Section 7: Conclusion

- a. I am satisfied/ not satisfied* that there is no commercial transaction from this organ donation.
 - b. I am satisfied/ not satisfied* that the prospective donor understands economic and social implications as a result to this organ donation.
 - c. I am satisfied/ not satisfied* that the prospective donor has adequate economic resources to deal with potential effects as a result to this organ donation.
 - d. I am satisfied/ not satisfied* that family members can provide adequate support to the prospective donor should any economic or social implication arise as a result to this organ donation.

I support/do not support the application of this organ donation because:

(signature of the medical social work officer)

Name :

IC :

Designation :

Institution :

* Delete whichever not applicable

Appendix 9

Translated form – Borang B (UTAC):
Deklarasi oleh Bakal Penderma



DEKLARASI OLEH BAKAL PENDERMA

Borang ini perlu diisi oleh bakal penderma organ dengan disaksikan oleh doktor yang bertanggungjawab terhadap beliau. Doktor yang bertanggungjawab terhadap bakal penderma dan doktor yang bertanggungjawab terhadap bakal penerima hendaklah individu yang berlainan.

Borang ini bukan borang kebenaran untuk menjalani pembedahan menderma organ. Sekiranya permohonan ini diluluskan, borang kebenaran yang berlainan perlu diisi dan ditandatangani oleh bakal penderma.

No. kes	:
Tarikh pemohonan	:

Bahagian 1: Maklumat untuk bakal penderma

1. Pemindahan organ yang melibatkan penderma yang tidak ada kaitan hanya dibenarkan jika kelulusan daripada Jawatankuasa Melulus Transplantasi dari Penderma Hidup Tiada kaitan Keluarga atau Unrelated Transplant Approval Committee (UTAC) telah diperolehi. Kelulusan ini hanya akan diterima jika kesemua garispanduan serta peruntukan di dalam Polisi Transplantasi Organ, Tisu dan Sel Kebangsaan telah dipenuhi. Adalah dinyatakan bahawa doktor yang bertanggungjawab terhadap anda yang akan menentukan sama ada anda sesuai dan sihat untuk menjadi penderma atau tidak. Doktor yang bertanggungjawab terhadap anda adalah bertanggungjawab sepenuhnya untuk memberikan penerangan mengenai risiko, peratus kejayaan pembedahan, kesan akibat menderma serta perkara yang perlu dilalui jika ingin menjadi seorang penderma.
2. Adalah menjadi tanggungjawab anda untuk menentukan keputusan tindakan anda. Anda berhak untuk menukar keputusan anda dari menjadi penderma pada bila-bila masa walaupun ketika pembedahan ingin dilakukan tanpa sebarang alasan perlu diberikan.
3. Polisi Transplantasi Organ, Tisu dan Sel Kebangsaan milarang sebarang bentuk pembayaran atau kepentingan yang lain bagi tujuan untuk mendapatkan organ. Tiada sesiapa dibenarkan sama sekali termasuk penerima memberikan sebarang tekanan kepada anda untuk menderma melalui sebarang paksaan kepada anda atau sesiapa yang ada kaitan dengan anda (contohnya ahli keluarga).
4. "Kepentingan lain" adalah termasuk janji bagi kenaikan pangkat, kerja yang lebih menarik, rumah untuk anda atau ahli keluarga atau sesiapa yang berkaitan dengan anda. Anda mungkin diberikan bayaran balik (reimbursement) sebagai ganti kos perbelanjaan yang di tanggung oleh anda dari pihak ketiga yang asing dari penerima tetapi sebarang keuntungan adalah tidak dibenarkan sama sekali.
5. Jika UTAC berpuashati dengan maklumat yang diberikan, anda sebagai penderma dikehendaki menandatangani deklarasi. Sebelum menandatangani deklarasi ini, pastikan anda telah menerima risalah mengenai "Pendermaan Organ Semasa Hidup" dan anda telah membacanya, faham akan isi kandungannya serta segala pertanyaan anda telah terjawab. Doktor yang bertanggungjawab terhadap anda mestilah hadir bersama ketika anda menandatangani deklarasi ini.

Bahagian 2: Maklumat peribadiGambar bakal
penderma

Nama :

No. KP :

Alamat :

No. tel (rumah) :

No. tel (bimbit) :

Emel :

Bangsa :

Agama :

Jantina :

Warganegara :

Tarikh lahir :

Tempat lahir :

Tahap pendidikan :

Status perkahwinan :

Pekerjaan :

Pendapatan bulanan :

Bahagian 3: Deklarasi bakal penderma

Adalah ini dinyatakan bahawa saya akan mendermakan organ saya iaitu
(nyatakan jenis organ) kepada
(nama/no.KP bakal penerima).

Saya mengaku bahawa saya, telah membaca Bahagian 1 borang ini/Bahagian 1 borang ini telah diterjemahkan kepada saya dan saya mengaku bahawa:

1. Faham akan segala kehendak yang dinyatakan dalam borang ini.
2. Tidak ada sebarang bayaran atau kepentingan lain yang akan diterima oleh saya atau sesiapa yang ada kaitan dengan saya.
3. Bahawasanya tidak ada sebarang paksaan keatas saya untuk mendermakan organ.
4. Bahawasanya tidak ada sebarang janji untuk sebarang imbuhan dan tiada sesiapa yang akan mendapat sebarang imbuhan dengan persetujuan saya untuk menderma.
5. Saya telah diberikan penerangan yang sepenuhnya mengenai prosedur pemindahan, risiko yang wujud jika saya mendermakan(nyatakan jenis organ) dan penerangan mengenai perkara ini telah diberikan kepada saya oleh(nyatakan nama doktor).
6. Saya faham akan prosedur pemindahan serta risiko yang akan timbul seperti mana yang diterangkan oleh doktor.
7. Saya bersetuju untuk mendermakan(nyatakan jenis organ).
8. Saya faham bahawa saya berhak untuk menarik diri dari menderma pada bila-bila masa tanpa perlu memberikan sebarang alasan.
9. Saya faham bahawa maklumat yang saya berikan adalah bagi kegunaan UTAC dan ianya adalah sulit.
10. Bagi menandatangani deklarasi ini, saya perlu/tidak perlukan* sebarang bantuan penterjemah.
11. Bahawasanya saya telah menerima risalah mengenai "Pendermaan Organ Semasa Hidup".

.....
(tandatangan bakal penderma)

Nama :

No. KP :

Tarikh :

* Potong yang tidak berkenaan

Bahagian 4: Deklarasi doktor yang bertanggungjawab terhadap bakal penderma

Dengan ini saya mengesahkan:

1. Bahawasanya saya adalah doktor yang bertanggungjawab terhadap penderma yang telah menandatangani Bahagian 3 borang ini.
2. Penerangan mengenai prosedur pembedahan serta risiko akibat mendermakan (*nyatakan jenis organ*) telah diberikan oleh saya/pengamal perubatan (*nama pengamal perubatan berdaftar*).
3. Bantuan penterjemah tidak diperlukan/ diperlukan (seperti yang dinyatakan di Bahagian 5)*.
4. Sepanjang pengetahuan saya deklarasi yang dibuat oleh penderma adalah benar dan saya merupakan saksi bagi beliau semasa menandatangi Bahagian 3.
5. Saya telah memberikan risalah “Pendermaan Organ Semasa Hidup” kepada penderma.

.....
(tandatangan doktor yang bertanggungjawab
terhadap bakal penderma)

Nama :

No. KP :

No. MPM :

Jawatan :

Institusi :

* Potong yang tidak berkenaan

Bahagian 5: Deklarasi penterjemah (jika berkaitan)

Saya dengan ini mengesahkan bahawa:

1. Saya merupakan penterjemah bagi (*nyatakan bahasa terjemahan*).
2. Saya tidak mengenali atau dikenali sama ada oleh bakal penderma atau bakal penerima.
3. Saya telah menterjemahkan segala maklumat yang terdapat di Bahagian 1, Bahagian 2 dan Bahagian 3 borang ini dan saya percaya bahawa penderma telah faham akan segala isi kandungannya dan beliau telah menandatangani borang ini secara sukarela tanpa melibatkan sebarang paksaan.

.....
(tandatangan penterjemah)

Nama :

No. Kp :

Jawatan :

Alamat :

.....

No. tel (rumah) :

No. tel (bimbit) :

Emel :

Tarikh :

Appendix 10

Translated form – Borang C (UTAC):
Deklarasi oleh Bakal Penerima



PERMOHONAN OLEH BAKAL PENERIMA

Borang ini perlu diisi oleh bakal penerima organ dengan disaksikan oleh doktor yang bertanggungjawab terhadap beliau. Doktor yang bertanggungjawab terhadap bakal penderma dan doktor yang bertanggungjawab terhadap bakal penerima hendaklah individu yang berlainan.

Borang ini bukan borang kebenaran untuk menjalani pembedahan menderma organ. Sekiranya permohonan ini diluluskan, borang kebenaran yang berlainan perlu diisi dan ditandatangani oleh bakal penerima.

No. kes	:
Tarikh pemohonan	:

Bahagian 1: Maklumat untuk bakal penerima

1. Pemindahan organ yang melibatkan penderma yang tidak ada kaitan hanya dibenarkan jika kelulusan daripada Jawatankuasa Melulus Transplantasi dari Penderma Hidup Tiada kaitan Keluarga atau Unrelated Transplant Approval Committee (UTAC) telah diperolehi. Kelulusan ini hanya akan diterima jika kesemua garispanduan serta peruntukan di dalam Polisi Transplantasi Organ, Tisu dan Sel Kebangsaan telah dipenuhi. Adalah dinyatakan bahawa doktor yang bertanggungjawab terhadap anda yang akan menentukan sama ada anda sesuai dan sihat untuk menjadi penderma atau tidak. Doktor yang bertanggungjawab terhadap anda adalah bertanggungjawab sepenuhnya untuk memberikan penerangan mengenai risiko, peratus kejayaan pembedahan, kesan akibat menderma serta perkara yang perlu dilalui jika ingin menjadi seorang penderma.
2. Adalah menjadi tanggungjawab anda untuk menentukan keputusan tindakan anda. Anda berhak untuk menukar keputusan anda dari menjadi penderma pada bila-bila masa walaupun ketika pembedahan ingin dilakukan tanpa sebarang alasan perlu diberikan.
3. Polisi Transplantasi Organ, Tisu dan Sel Kebangsaan milarang sebarang bentuk pembayaran atau kepentingan yang lain bagi tujuan untuk mendapatkan organ. Tiada sesiapa dibenarkan sama-sekali termasuk penerima memberikan sebarang tekanan kepada anda untuk menderma melalui sebarang paksaan kepada anda atau sesiapa yang ada kaitan dengan anda (contohnya ahli keluarga).
4. “Kepentingan lain” adalah termasuk janji bagi kenaikan pangkat, kerja yang lebih menarik, rumah untuk anda atau ahli keluarga atau sesiapa yang berkaitan dengan anda. Anda mungkin diberikan bayaran balik (reimbursement) sebagai ganti kos perbelanjaan yang ditanggung oleh anda dari pihak ketiga yang asing dari penerima tetapi sebarang keuntungan adalah tidak dibenarkan sama sekali.
5. Jika UTAC berpuashati dengan maklumat yang diberikan, anda sebagai penderma dikehendaki menandatangani deklarasi. Sebelum menandatangani deklarasi ini, pastikan anda telah menerima risalah mengenai “Pendermaan Organ Semasa Hidup” dan anda telah membacanya, faham akan isi kandungannya serta segala pertanyaan anda telah terjawab. Doktor yang bertanggungjawab terhadap anda mestilah hadir bersama ketika anda menandatangani deklarasi ini.

Bahagian 2: Maklumat peribadiGambar bakal
penderma

Nama :

No. KP :

Alamat :

.....

No. tel (rumah) :

No. tel (bimbit) :

Emel :

Bangsa :

Agama :

Jantina :

Warganegara :

Tarikh lahir :

Tempat lahir :

Status perkahwinan :

Pekerjaan :

Pendapatan bulanan :

Bahagian 3: Deklarasi Bakal Penerima

Adalah dinyatakan bahawa saya bersetuju untuk menerima organ (*nyatakan jenis organ*) daripada penderma hidup bernama (*nama/no.KP bakal penderma*).

Saya mengaku bahawa saya, telah membaca Bahagian 1 borang ini/ Bahagian 1 borang ini* telah diterjemahkan kepada saya dan saya mengaku bahawa:

1. Saya faham akan segala kehendak yang dinyatakan dalam borang ini.
2. Tidak ada sebarang bayaran atau kepentingan lain seperti yang dinyatakan di Bahagian 1 yang akan ditawarkan oleh saya atau sesiapa yang ada kaitan dengan saya kepada penderma bagi mendapatkan organ penderma.
3. Bahawasanya tidak ada sebarang bentuk paksaan yang telah dibuat oleh saya atau sesiapa sahaja kepada penderma untuk mendermakan organ.
4. Bahawasanya tidak ada sebarang janji daripada saya atau sesiapa sahaja untuk memberikan imbuhan atau bayaran kepada penderma bagi mendapatkan persetujuannya untuk mendermakan organnya.
5. Saya faham bahawa maklumat yang saya berikan adalah bagi kegunaan UTAC dan ianya adalah sulit.
6. Bagi menandatangani deklarasi ini saya perlu/tidak perlukan sebarang bantuan penterjemah.

.....
(tandatangan bakal penerima)

Nama :

No. KP :

Tarikh :

* Potong yang tidak berkenaan

Bahagian 4: Deklarasi doktor yang bertanggungjawab terhadap bakal penderma

Saya dengan ini mengesahkan:

1. Saya adalah doktor yang bertanggungjawab terhadap penerima yang telah menandatangani Bahagian 3 borang ini.
2. Sepanjang pengetahuan saya deklarasi yang dibuat oleh penerima adalah benar dan saya merupakan saksi bagi beliau.
3. Penerangan mengenai prosedur pembedahan serta risiko akibat mendermakan (*nyatakan jenis organ*) telah diberikan oleh saya/pengamal perubatan..... (*nama pengamal perubatan berdaftar*).
4. Bantuan penterjemah tidak diperlukan/diperlukan (seperti yang dinyatakan di Bahagian 5)*.

.....
(tandatangan doktor yang bertanggungjawab
terhadap bakal penerima)

Nama :

No. KP :

No. MPM :

Jawatan :

Institusi :

Appendix 11

Public Information Leaflet – Living Organ Donation

LIVING ORGAN DONATION

What you need to know...

1. Introduction

The purpose of this booklet is to help you and your family understand what it means to be a living organ donor. It also provides specific information on unrelated living organ donation. In the event if you need any further information/clarification, please consult your doctor. Your doctor will discuss this with you personally, but we also want you to have something you can take with you to read. Please keep this booklet for your further reference.

2. What is organ transplant?

Organ transplantation is the replacement of diseased and damaged organs. It is an established treatment for end stage organ failure. Organs for transplantation can be obtained from live or deceased donors.

3. What is organ donation?

Organ donation is a surgical procedure for the removal of organs from donor for the purpose of transplantation. Organ donation saves lives and improves quality of life.

Organ donation in Malaysia is voluntary where expressed consent is required.

There are two types of organ donation;

Deceased Organ Donation (from someone who has died)

- Malaysia practices an opting in system.
- In this case, an organ is removed from a person after his death.
- Retrieval of organ requires consent from family members.
- Someone who has died may donate both kidneys, liver, heart, lungs and also tissues like cornea (eye), skin, heart valves and bones.

Living Organ Donation

- A person (donor) chooses to donate one of their kidneys or part of their liver while the donor is still alive.
- The donor is usually a blood relative or spouse to the recipient.
- This type of transplant requires planning.
- Living donor remains an important source of organ due to shortage organ from deceased donors.

The major public transplant centres in this country are;

Hospital Kuala Lumpur	Kidney Transplantation
Hospital Selayang	Kidney Transplantation Liver Transplantation
University Malaya Medical Centre	Kidney Transplantation
National Heart Institute (in collaboration with Respiratory Medicine Institute)	Heart & Lungs Transplant

4. What are the advantages of living donor transplant?

a. Shorter waiting time

A patient with kidney failure usually waits for several years to receive deceased donor kidneys. However, with a suitable living donor such transplant can be done within weeks.

b. Living donation is an elective surgery

This means the transplant surgery can be done when both donor and recipient are in the best of health for surgery. Living donor transplant surgery can be electively scheduled to suit the donor and recipient.

c. Organs from living donors work better

Most of the time the kidney from living donor works immediately after surgery and continues to work better and longer than kidney from a deceased donor.

5. Who can be a living donor?

In Malaysia, the Ministry of Health allows living organ donation only to your close blood relative. This includes your identical twin, your first degree relative and your second degree relative. You may also donate to your legal spouse (husband/wife). If you wish to donate your organ to someone who is not genetically related to you or to a distant relative (a third degree relative and beyond), you will need to be evaluated by an Independent Committee appointed by the Ministry of Health. Following this evaluation, permission may or may not be granted.

Who are my first and second degree relatives?¹

FIRST DEGREE

Mother	Father
Daughter	Son
Full sister	Full brother

SECOND DEGREE

Grandmother	Grandfather
Granddaughter	Grandson
Aunt	Uncle
Niece	Nephew
Half sister	Half brother

6. Who cannot donate organs² ?

In this country, children³ and mentally disordered persons⁴ are not allowed to donate organs while they are still alive. Prisoners are also not allowed to donate organs unless in life threatening circumstances involving close relatives. This is subject to approval by the Ministry of Health and other relevant authorities.

Of course, those with certain medical conditions are also not allowed to donate their organs (please refer to the next section). These medical conditions may be discovered during the evaluation process of living donors.

7. What is UTAC and what are the procedures?

UTAC stands for Unrelated Transplant Approval Committee (UTAC). UTAC is an independent committee set up by the Ministry of Health to evaluate every application for unrelated living organ donation. You cannot apply directly to UTAC, only the doctor responsible for you as the potential donor or a doctor responsible for the potential recipient can apply to UTAC. The doctor needs to do a preliminary assessment on you to determine your suitability to be a living donor. If the doctor is satisfied with your suitability, he/she will then apply to UTAC by filling in some official forms.

You will then have to undergo a series of interviews with independent donor advocates.

¹ National Genetic Education and Development Centre, National Health Service UK.

² The National Organ Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, 2007.

³ According to Child Act 2001 [Act 611], a child is defined as someone who is less than 18 years old.

⁴ According to Mental Health Act 2001 [Act 615], a mentally disordered person means a person with any mental illness, arrested or incomplete development of mind, psychiatric disorder or any other disorder or disability of the mind however acquired.

8. Will I be paid for donating my organ?

The sale of organ and tissues is prohibited. A gift of life by someone who has donated his/her organ is priceless. The Ministry of Health will not pay you for your organ. Similarly someone who receives your organ should not pay you in return. Any other form of money worth rewards or non financial inducements are also not allowed. These include, among others, job promotion, house, cars, land and others.

However, reasonable reimbursement related to the donation process is permissible. In the Ministry of Health's hospitals, all charges pertaining to organ donation surgery including ward admission are waived¹. If you are a public service personnel, you are also entitled to unrecorded leave for not more than 42 days² during the recovery period.

The Ministry is committed, together with the World Health Organization,³ in preventing trading of human organs.

As for the Muslims; while donating of organ is permissible ("harus"), trading of organ is prohibited ("haram")⁴.

9. Am I fit to become a living donor?

Living donors should be in good overall physical and mental health. Certain medical conditions like diabetes mellitus, cancer, HIV infection, hepatitis, and organ diseases will preclude you from becoming a donor. It is extremely important that you inform the donor evaluation team (doctors or nurses) about your physical and mental health.

You need to complete a full medical and psychosocial evaluation and also be fully informed of the risks involved. Your decision to be a donor should be completely voluntary and free of pressure or guilt.

If you decide to be a living donor, a "living donor advocate" may assist you. The living donor advocate will promote your best interests regarding living donation and assist you in obtaining and understanding information regarding the evaluation

process, surgical procedure and follow-up. The donor advocate is not involved with the potential recipient evaluation and remains independent of the decision to transplant.

You can change your mind and decide not to donate your organ at any time during the evaluation process. Your reason not to donate shall be kept confidential.

10. What are the risks of living organ donation?

Most donors recover fully after the surgery and can do normal activities within a few weeks after the surgery. Recovery period for liver donation is slightly longer than kidney donation. Organ donation will not change your lifestyle in a big way. There's no evidence that it will change your life expectancy. Woman can still have children. As for kidney donation, it does not increase your risk of getting kidney disease in your other kidney. In fact, some people are born with only one kidney and live a completely normal life.

However, as with any major surgery, there are risks.



¹ Refer to circular "Kementerian Kesihatan Malaysia – Pengecualian Bayaran Bil Hospital bagi Pesakit Penderma Organ, ref: (95)dlm.KKM-203/19Jld.4, 29 December 2003"

² Refer to circulars "Surat Pekeliling Ketua Pengarah Kesihatan Bilangan 6 Tahun 2010, 24 February 2010" and "Pekeliling Perkhidmatan JPA Bilangan 3 Tahun 2010, 2 February 2010"

³ WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation, May 2010

⁴ National Fatwa Council 1970

Mortality risk for organ donation differs between kidney and liver donation:

Type of organ donation	Donor mortality risk
Kidney donation	3.1 deaths in 10,000 donation ¹
Liver donation	Right lobe liver: 1 death in 200 donation ² Left lobe liver: 1 death in 1000 donation

Other risks associated with the surgery include

- Pain or numbness around the incision area.
- Lung, urinary tract and wound infection. The chances of developing a lung infection can be reduced by breathing exercise.
- Bleeding is uncommon. However, you may require a blood transfusion if necessary. It is important you also understand the risks associated with blood transfusion.
- Blood clots may occur in your legs (called Deep Vein Thrombosis) which may travel to the lung. This can be life threatening. You will be advised to wear compression stockings and ambulate early after surgery to prevent this from happening.
- Anaesthetic complication including allergic reactions to anaesthetic drugs.
- Injury to surrounding tissue or other organs.
- Hernia. You should not do heavy lifting for four to six weeks after surgery to avoid this problem.

Negative psychological symptoms are possible during the healing process and even years after the donation. Your donated organ may not function in the recipient after it is transplanted. Scarring or other aspects of the donation process could possibly contribute to problems with body image. You may have feelings of regret, resentment or anger. You may develop anxiety and depression. Treatment of these conditions can be lengthy and you may experience side effects of the medications used.

Long-term risk

Based upon available information, overall risks are considered to be low. Risks can differ among donors. Risks can also differ according to the type of organ you donate.

Your doctor will explain to you more about the risks during the evaluation process.

11. What do I need to know about living donor evaluation process?

You will be meeting the transplant team for consultations and have several tests performed before donating an organ. Most of the tests are done on an outpatient basis. These are done to ensure your fitness and suitability to undergo the surgery.

During the first consultation with the donor, comprehensive medical history will be obtained.

Your blood and the recipient blood will be taken for compatibility test. The initial tests are:

- Blood type: O,A,B or AB
- HLA cross match
- HLA typing

Compatibility test will help to determine the risk of organ rejection. This will guide the transplant team on the level of anti-rejection drugs or immunosuppression to be used in the recipient.

Once the initial tissue typing has been completed and a compatible potential donor is identified, the medical evaluation of that potential donor can continue. This evaluation can take place at the transplant centers, or if the donor lives far away, many of these tests can be performed at the nearby hospital. The additional tests include:

¹ "Perioperative Mortality and Long Term Survival Following Live Kidney Donation" in Journal of the American Medical Association, Vol. 303, No. 10, March 10, 2010.

² "Live Donor Liver Transplantation" in Journal of Liver Transplantation, Vol. 12, 2006

ADDITIONAL BLOOD TEST	<ul style="list-style-type: none"> • This is to screen for transmissible diseases like HIV, Hepatitis B and others. • This is also to assess your medical status such as presence of diabetes, heart disease and others.
URINE TEST	<ul style="list-style-type: none"> • In particular for kidney donation, 24 hours urine sample will be taken to assess your kidney function or presence of kidney stones. Usually three samples are taken.
CHEST X-RAY	<ul style="list-style-type: none"> • This is to assess your lungs and your heart .
ELECTROCARDIOGRAM (ECG)	<ul style="list-style-type: none"> • This is to screen for heart disease. Based on the ECG finding and other clinical reasons, further test may be required for evaluation of the heart such as stress test.
ULTRASOUND AND OTHER IMAGING LIKE CT SCAN	<ul style="list-style-type: none"> • This is assess your liver and/or you kidney.
CANCER SCREENING	<ul style="list-style-type: none"> • Types of test will be determined by your transplant team.
PSYCHOSOCIAL AND PSYCHOLOGICAL EVALUATION	<ul style="list-style-type: none"> • This is to assess your mental health, you ability to understand all information given and make an informed decision. The team will also assess your daily life circumstances.
CONSULTATION	<ul style="list-style-type: none"> • The transplant team including surgeon will give you further consultation and perform physical examination. Surgeon will explain about the nature of the surgery and risks.
OTHERS	<ul style="list-style-type: none"> • Some doctors may do liver biopsy for liver donation.

12. What do I need to know about the surgical procedures?

Kidney donation

There are two types of surgery for kidney donation; laparoscopic and open flank approach surgery.

Open flank surgery is a traditional approach which involves flank incision about 15-20 cm on either your right or left side. Both the skin and muscle need to be cut in order to reach your kidney.

Laparoscopic surgery involves the use of tube-like instruments. The use of laparoscopic instruments allows the kidney to be removed through a smaller incision. The major benefits of this type of surgery are faster recovery time and less discomfort for the donor.

The surgical team will suggest to you types of surgery depending on level of expertise and suitability of the donor and/or kidney.

Liver donation

The surgeon will make an incision on your abdomen approximately 2 fingers width below the rib cage. The length will depend on your body size. Either left or right lobe of your liver will be taken depending on the size of the recipient (usually right lobe is for adult recipient and left lobe is for the paediatric recipient). The incision will be closed with stitches or staples.

You surgeon and anaesthetist will explain to you further on what you should do before and after the surgery.

13. Where can I get more information?

If you want more information about living organ donation, you may contact:

NATIONAL TRANSPLANT RESOURCE CENTRE

Hospital Kuala Lumpur
Jalan Pahang, 50586 Kuala Lumpur

Email : ntrc@hkl.moh.gov.my
Tel. (office) : (603) 26942704/2705
Tel. (fax) : (603) 26156269
Tel (toll free) : 1-800-88-9080
Website : www.agiftoflife.gov.my

You may also consult any kidney or liver specialist nearest to you.

This leaflet was designed to provide basic information to the public and prospective living organ donors about living organ donation. It is part of requirements in the Ministry of Health's guidelines "Unrelated Living Organ Donation: Policy and Procedures" that the doctor responsible for the prospective donor should provide the donor with this leaflet for further reading. This should not undermine the importance of verbal communication and consultations pertaining to risks and benefits of living organ donation. If necessary, assistance from an independent interpreter shall be obtained to translate information in this leaflet. The prospective living donor shall be provided with other relevant information to enable him/her to make an informed consent.

This information leaflet was developed by the Medical Development Division, Ministry of Health Malaysia. For any feedback please email to transplantation_unit@moh.gov.my, or write and address to Transplantation Unit, Level 5, Block E1, Complex E, Federal Government Administrative Centre, 62590 Putrajaya Malaysia.

WORKING GROUP:

Dr Hirman Ismail, Dr Rosnawati Yahya, Datuk Dr Harjit Singh, Datuk Dr Ghazali Ahmad, Dr Wong Hin Seng, Dato' Dr Rohan Malek, Datin Dr Fadhilah Zowyah Lela Yasmin Mansor, Dr Tan Chwee Choon, Matron Jamaliah Kario.

All rights reserved. © 2011 Medical Development Division, Ministry of Health Malaysia.



MINISTRY OF HEALTH MALAYSIA
www.moh.gov.my

PENDERMAAN ORGAN SEMASA HIDUP

Maklumat untuk anda...

1. Pengenalan

Risalah ini bertujuan untuk memberi maklumat kepada anda dan ahli keluarga anda mengenai pendermaan organ semasa hidup ("living organ donation"). Risalah ini juga akan membincangkan mengenai pendermaan organ semasa hidup dari kalangan mereka yang tidak mempunyai hubungan kekeluargaan. Sekiranya ada perlu maklumat lanjut, sila hubungi doktor anda. Doktor anda akan memberi penjelasan lanjut. Sila simpan risalah ini sebagai rujukan.

2. Apakah itu pemindahan organ?

Pemindahan organ adalah suatu pembedahan bagi menggantikan organ yang bermasalah atau berpenyakit dengan organ yang baru. Organ yang digunakan untuk pemindahan ini datang dari dua sumber iaitu (1) dari penderma organ yang masih hidup ("living donor") dan (2) dari penderma yang sudah meninggal dunia ("deceased donor").

3. Apa itu pendermaan organ?

Pendermaan organ adalah suatu prosedur pembedahan yang melibatkan pemindahan organ dari penderma kepada penerima organ. Pendermaan organ dapat menyelamatkan nyawa dan mempertingkatkan kualiti hidup penerima organ.

Terdapat dua jenis pendermaan organ;

Pendermaan Organ Kadaverik (setelah meninggal dunia)

- Di dalam kes seumpama ini, organ dikeluarkan selepas penderma meninggal dunia.
- Kebenaran ahli keluarga si mati boleh memberi keizinan untuk pendermaan organ.
- Seseorang yang telah meninggal dunia boleh mendermakan buah pinggang, hati, jantung, paru-paru dan juga tisu seperti kornea (mata), kulit, injap jantung dan tulang.

Pendermaan Organ Semasa Hidup

- Seseorang yang masih hidup boleh mendermakan sebahagian dari hatinya ("liver") atau salah satu buah pinggang.
- Penderma organ pada kebiasaan adalah ahli keluarga atau pasangan suami isteri.
- Pendermaan organ dari penderma hidup melibatkan perancangan tertentu.
- Pendermaan organ dari penderma hidup adalah sumber organ yang penting memandangkan kekurangan organ dari penderma kadaverik.

Hospital kerajaan utama yang menjalankan pembedahan transplan organ adalah;

Hospital Kuala Lumpur	Pemindahan Buah Pinggang
Hospital Selayang	Pemindahan Buah Pinggang Pemindahan Hati
Pusat Perubatan Universiti Malaya	Pemindahan Buah Pinggang
Institut Jantung Negara (in collaboration with Respiratory Medicine Institute)	Pemindahan Jantung & Paru-Paru

4. Apakah kelebihan pembedahan transplan dari penderma organ yang masih hidup?

- a. Mengurangkan masa menunggu pesakit
Pesakit yang menghidapi kegagalan fungsi buah pinggang terpaksa menunggu sehingga beberapa tahun sebelum mendapat buah pinggang dari penderma kadaverik. Walau bagaimanapun, bagi pendermaan organ semasa hidup, pembedahan transplan dapat dilakukan pada waktu yang sesuai.
- b. Pembedahan dilakukan secara elektif
Ini bermakna pembedahan transplan dapat dilakukan semasa penderma dan penerima berada dalam keadaan kesihatan yang sesuai untuk menjalankan pembedahan. Pembedahan boleh dilakukan mengikut masa yang sesuai untuk penderma dan penerima organ.
- c. Organ dari penderma hidup berfungsi lebih baik
Kebanyakan buah pinggang dari penderma hidup dapat berfungsi dengan baik sejurus selepas pembedahan transplan dilakukan. Buah pinggang ini juga terus berfungsi dengan lebih lama dan lebih baik berbanding organ dari penderma kadaverik.

5. Siapakah yang boleh menderma organ?

Di Malaysia, Kementerian Kesihatan Malaysia hanya membenarkan pendermaan organ semasa hidup kepada ahli keluarga terdekat yang mempunyai pertalian darah. Ini termasuk pasangan kembar seiras, ahli keluarga darjah pertama ("first degree relative") dan ahli keluarga darjah kedua ("second degree relative"). Anda juga boleh menderma kepada suami atau isteri yang sah. Sekiranya anda muhu menderma organ kepada seseorang yang tidak mempunyai pertalian darah atau ahli keluarga yang jauh (ahli keluarga darjah ketiga ke atas), anda perlu menjalani penilaian oleh satu Jawatankuasa bebas dilantik oleh pihak Kementerian Kesihatan Malaysia. Anda mungkin diberikan kelulusan untuk pendermaan organ berdasarkan kepada penilaian Jawatankuasa bebas tersebut.

Siapa ahli keluarga terdekat saya terdekat ?¹

"FIRST DEGREE"

Ibu	Bapa
Anak perempuan	Anak lelaki
Kakak	Abang

"SECOND DEGREE"

Nenek	Datuk
Cucu perempuan	Cucu lelaki
Ibu saudara	Bapa saudara
Anak saudara perempuan	Anak saudara lelaki
Kakak tiri	Abang tiri

6. Siapa yang tidak boleh menderma organ?²

Di Malaysia, kanak-kanak³ dan orang kurang upaya mental⁴ tidak dibenarkan untuk menderma organ semasa mereka masih hidup. Banduan penjara juga tidak dibenarkan untuk menderma organ kecuali di dalam keadaan tertentu melibatkan nyawa ahli keluarga terdekat. Walau bagaimanapun, proses pendermaan organ ini masih memerlukan kelulusan dari Kementerian Kesihatan Malaysia dan lain-lain badan berkuasa yang berkaitan.

Seseorang yang mempunyai masalah kesihatan tertentu juga tidak dibenarkan untuk menderma organ (sila rujuk bahagian selanjutnya). Masalah kesihatan ini ada kalanya boleh dikesan semasa proses penilaian penderma dijalankan.

7. Apa yang dimaksudkan dengan UTAC dan apakah prosedur yang berkaitan?

UTAC atau nama penuhnya "Unrelated Transplant Approval Committee" merupakan sebuah Jawatankuasa bebas yang ditubuhkan di peringkat Kementerian Kesihatan Malaysia bagi menilai setiap permohonan untuk menjalankan pembedahan transplant organ dari penderma yang masih hidup yang tidak mempunyai hubungan kekeluargaan. Sekiranya anda ingin menjadi seorang penderma, anda tidak boleh membuat permohonan secara terus kepada UTAC. Doktor yang bertanggungjawab terhadap anda atau penerima organ yang boleh membuat permohonan kepada UTAC. Doktor tersebut perlu menjalankan ujian-ujian untuk menilai kesesuaian anda sebagai seorang penderma. Jika doktor anda berpuashati dengan penilaian awal ini, beliau akan membuat permohonan dengan mengisi beberapa borang rasmi. Anda perlu menjalani beberapa sesi penilaian bersama pakar sebelum UTAC membuat keputusan mengenai sesuatu permohonan.

¹ National Genetic Education and Development Centre, National Health Service UK.

² Polisi Transplantasi Organ Tisu dan Sel Kebangsaan, Kementerian Kesihatan Malaysia, 2007.

³ Menurut Akta Kanak-Kanak 2001 [Akta 611], kanak-kanak ertiaya seseorang yang di bawah umur lapan belas tahun.

⁴ Menurut Akta Kesihatan Mental 2001 [Akta 615], "a mentally disordered person means a person with any mental illness, arrested or incomplete development of mind, psychiatric disorder or any other disorder or disability of the mind however acquired".

8. Bolehkah seseorang penderma organ diberi bayaran?

Jualbeli organ adalah dilarang. Pengorbanan seseorang yang telah menderma organ adalah tidak ternilai harganya. Kementerian Kesihatan tidak akan membuat sebarang bayaran sekiranya anda telah menderma organ. Pesakit yang menerima organ tersebut juga tidak dibenarkan membuat sebarang bayaran kepada penderma. Selain itu, pemberian hadiah ataupun sebarang insentif bukan berbentuk kewangan juga adalah dilarang. Ini termasuk pemberian rumah, kereta, tanah, kenaikan pangkat dan lain-lain.

Walau bagaimanapun, pemberian bantuan yang berkaitan dengan proses pendermaan adalah dibenarkan dan bentuk bantuan ini perlu munasabah dan tidak keterlaluan. Di hospital Kementerian Kesihatan, semua bayaran bil hospital berkaitan dengan pembedahan pendermaan organ termasuk caj wad adalah dikecualikan¹ untuk penderma organ. Sekiranya anda seorang penjawat awam, anda layak untuk diberikan cuti tanpa rekod untuk tempoh tidak lebih dari 42 hari² semasa tempoh pemulihan selepas pembedahan.

Kementerian Kesihatan sentiasa komited bersama-sama dengan Pertubuhan Kesihatan Sedunia³ untuk membanteras perdagangan organ manusia.

Bagi yang beragama Islam, pendermaan organ adalah harus, manakala perdagangan organ adalah haram⁴.

9. Adakah saya sesuai untuk menderma organ?

Secara umumnya, seorang yang ingin menderma organ perlu sihat dari segi fizikal dan mental. Seseorang yang menghidap kencing manis, barah, jangkitan HIV, jangkitan hepatitis dan penyakit berkaitan organ tertentu, adalah tidak sesuai untuk menderma organ. Oleh itu, adalah penting untuk anda memaklumkan mengenai status kesihatan fizikal dan mental anda kepada doktor atau jururawat yang menjalankan penilaian.

Anda perlu melalui proses penilaian perubatan dan psikososial yang lengkap dan perlu dimaklumkan mengenai risiko pendermaan organ tersebut. Semasa proses penilaian, pakar perubatan yang menilai akan sentiasa mengambil kira kepentingan anda sebagai penderma organ. Pakar perubatan tersebut akan membantu anda mendapatkan maklumat serta memahami maklumat yang diberikan termasuk yang berkaitan dengan proses penilaian, prosedur pembedahan dan pemantauan susulan selepas menderma organ. Pakar perubatan tersebut tidak terlibat dengan rawatan bakal penerima organ dan oleh itu pakar tersebut bebas membuat keputusan mengenai penilaian yang dilakukan.

Anda juga berhak menarik balik keputusan untuk menderma organ pada bila-bila masa. Alasan untuk tidak menderma akan dirahsiakan.

10. Apakah risiko pendermaan organ semasa hidup?

Kebanyakan penderma pulih sepenuhnya dan boleh melakukan aktiviti harian seperti biasa beberapa minggu selepas pembedahan dijalankan. Tempoh pemulihan selepas pembedahan pendermaan hati adalah lebih panjang berbanding pendermaan buah pinggang. Secara umumnya, pendermaan organ tidak akan mengubah gaya hidup anda. Pendermaan organ juga tidak akan mengubah jangka hayat seseorang. Kaum wanita boleh hamil dan melahirkan anak seperti biasa. Pendermaan buah pinggang juga tidak meningkatkan risiko untuk mendapat penyakit buah pinggang pada masa akan datang. Sesetengah individu dilahirkan dengan hanya satu buah pinggang dan mereka dapat hidup normal seperti orang biasa.

Walau bagaimanapun, seperti prosedur pembedahan yang lain, prosedur pendermaan organ juga mempunyai risiko tertentu.

¹ Sila rujuk Pekeliling "Kementerian Kesihatan Malaysia – Pengecualian Bayaran Bil Hospital bagi Pesakit Penderma Organ, ref: (95)dlm.KKM-203/19Jld.4, 29 Disember 2003".

² Sila rujuk Pekeliling "Surat Pekeliling Ketua Pengarah Kesihatan Bilangan 6 Tahun 2010, 24 Februari 2010" dan "Pekeliling Perkhidmatan JPA Bilangan 3 Tahun 2010, 2 Februari 2010".

³ "WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation", Mei 2010.

⁴ Majlis Fatwa Kebangsaan 1970.

Risiko kematian adalah berbeza mengikut jenis organ:

Pendermaan organ	Risiko kematian penderma
Pendermaan buah pinggang	3.1 kematian dalam setiap 10,000 pendermaan ¹
Pendermaan hati	Bahagian kanan: 1 kematian dalam setiap 200 pendermaan ² Bahagian kiri: 1 kematian dalam setiap 1000 pendermaan

Lain-lain risiko berkaitan pembedahan adalah

- Rasa sakit dan kebas di sekitar luka pembedahan.
- Jangkitan paru-paru, saluran kencing dan luka pembedahan. Risiko mendapat jangkitan paru-paru boleh diatasi melalui cara pernafasan yang betul.
- Pendarahan kadang kala boleh berlaku. Sekiranya pendarahan berlaku, anda mungkin perlu mendapatkan transfusi darah. Oleh itu anda perlu memahami risiko transfusi darah.
- Darah beku di dalam salur pembuluh kaki atau lebih dikenali sebagai "Deep Vein Thrombosis". Darah beku ini boleh beralih ke paru-paru. Anda akan dinasihatkan memakai sarung kaki khas dan memperbanyakkan pergerakan bagi mengelak kejadian ini.
- Komplikasi anaesthesia atau ubat bius. Contohnya alahan terhadap ubat tersebut.
- Kecederaan kepada tisu dan organ lain semasa pembedahan.
- Hernia (angin pasang) di kawasan luka pembedahan. Anda dinasihatkan untuk tidak mengangkat benda-benda berat selama 4 hingga 6 minggu selepas pembedahan dijalankan.

Gejala psikologi yang negatif boleh terjadi semasa atau selepas beberapa tahun pembedahan dilakukan. Terdapat juga kemungkinan organ yang didermakan tidak berfungsi di dalam badan penerima. Parut

luka pembedahan juga boleh mengubah imej fizikal seseorang. Anda mungkin mempunyai perasaan menyesal, dendam dan marah disebabkan oleh pembedahan tersebut. Anda juga boleh mengalami masalah kemurungan. Rawatan kepada permasalahan ini mungkin mengambil masa yang panjang anda boleh mendapat kesan sampingan ubat yang diambil.

Risiko jangka masa panjang

Berdasarkan kepada maklumat yang sedia ada, risiko keseluruhan adalah rendah. Risiko adalah berbeza di kalangan penderma organ. Risiko juga berbeza bergantung kepada organ yang didermakan.

11. Bagaimana suatu proses penilaian penderma organ dilakukan?

Anda akan menemui pasukan pembedahan transplan di mana sesi perundingan dan beberapa ujian perlu dilakukan. Kebanyakan ujian dilakukan secara temujanji atau pesakit luar. Tujuan penilaian ini adalah untuk memastikan anda sesuai untuk menderma organ.

Semasa sesi penilaian yang pertama ke atas bakal penderma, latar belakang kesihatan akan diambil.

Darah anda dan penerima organ akan diambil untuk tujuan ujian kesepadan seperti:

- Jenis darah: A,B,O atau AB
- "HLA cross match"
- "HLA typing"

¹ "Perioperative Mortality and Long Term Survival Following Live Kidney Donation" in Journal of the American Medical Association, Vol. 303, No. 10, Mac 10, 2010.

² "Live Donor Liver Transplantation" in Journal of Liver Transplantation, Vol. 12, 2006.

Ujian kesepadan akan membantu menentukan risiko penolakan organ. Ia juga akan membantu doktor menentukan dos yang sesuai ubat anti-penolakan atau "immunosuppressant" untuk bakal penerima organ.

Setelah ujian kesepadan selesai, bakal penderma akan melalui ujian selanjutnya. Ujian-ujian selalunya akan dijalankan di hospital yang menjalankan pemindahan. Walau bagaimanapun, sekiranya bakal penderma tinggal berjauhan, sesetengah ujian ini boleh dilakukan di hospital yang berdekatan.

LAIN-LAIN UJIAN DARAH	<ul style="list-style-type: none"> Ini termasuk ujian untuk mengesan penyakit berjangkit seperti HIV, hepatitis dan lain-lain. Ujian darah dilakukan bagi mengesan kencing manis, masalah jantung dan lain-lain.
UJIAN AIR KENCING	<ul style="list-style-type: none"> Untuk pendermaan buah pinggang, sampel air kencing untuk tempoh 24 jam akan diambil bagi mengetahui tahap fungsi buah pinggang serta masalah batu karang. Kebiasaannya tiga sampel akan diambil.
X-RAY DADA	<ul style="list-style-type: none"> Ini adalah untuk menilai keadaan jantung dan paru-paru.
“ELECTROCARDIOGRAM” (ECG)	<ul style="list-style-type: none"> Ini merupakan ujian saringan penyakit jantung. Berdasarkan kepada keputusan ECG ini, lain-lain ujian lanjutan seperti ujian stress mungkin perlu dilakukan.
UJIAN ULTRASOUND DAN LAIN-LAIN UJIAN PENGIMEJAN SEPERTI IMBASAN CT	<ul style="list-style-type: none"> Ini bertujuan menilai keadaan buah pinggang dan juga hati.
UJIAN SARINGAN BARAH	<ul style="list-style-type: none"> Jenis-jenis ujian saringan ini bergantung kepada pasukan transplan.
PENILAIAN PSIKOLOGI DAN PSIKO-SOSIAL	<ul style="list-style-type: none"> Ini bertujuan menilai kesihatan mental anda, keupayaan anda untuk memahami maklumat yang diberikan dapat membuat keputusan sendiri berdasarkan maklumat yang diberikan. Mereka juga akan menilai keadaan kehidupan seharian anda.
SESI PERUNDINGAN	<ul style="list-style-type: none"> Sesi perundingan dan melakukan pemeriksaan fizikal. Pakar bedah akan menerangkan dengan lebih lanjut mengenai pembedahan dan risiko yang terlibat.
LAIN-LAIN	<ul style="list-style-type: none"> Sesetengah doktor akan melakukan ujian “liver biopsy” untuk pendermaan hati. Ujian ini melibatkan sedikit sampel hati diambil untuk pemeriksaan makmal.

12. Apakah yang perlu saya tahu mengenai prosedur pembedahan?

Pendermaan buah pinggang

Terdapat dua jenis pembedahan pendermaan buah pinggang; secara laparoskopi dan juga pembedahan secara biasa melalui abdomen anda.

Pembedahan biasa melibatkan bukaan pembedahan sepanjang 15-20cm pada bahagian kiri atau kanan abdomen. Kulit serta otot yang terlibat perlu dibedah bagi mengeluarkan buah pinggang.

Pembedahan secara laparoskopi melibatkan peralatan laparoskop iaitu sejenis alat yang berbentuk tiub. Penggunaan alat ini membolehkan luka pembedahan untuk mengeluarkan buah pinggang dilakukan lebih kecil. Kelebihan utama teknik pembedahan laparoskopik ini adalah tempoh pemulihan lebih cepat dan kurang rasa sakit.

Pakar bedah akan berbincang dengan anda mengenai jenis pembedahan yang sesuai bergantung kepada kepakaran yang ada serta kesesuaian penderma dan/atau buah pinggang.

Pendermaan hati

Pakar bedah akan membuat bukaan pembedahan pada abdomen. Panjang luka pembedahan ini bergantung kepada saiz penderma. Sama ada bahagian kanan atau kiri hati akan dikeluarkan bergantung kepada saiz penerima organ (pada kebiasaannya bahagian kanan adalah untuk penerima dewasa dan bahagian kiri untuk penerima kanak-kanak).

Pakar bedah dan pakar bius akan menjelaskan dengan lebih lanjut mengenai perkara yang perlu dilakukan sebelum dan selepas pembedahan.

13. Di mana boleh saya dapatkan maklumat lanjut?

Maklumat lanjut boleh diperolehi dari:

PUSAT SUMBER TRANSPLAN NASIONAL

Hospital Kuala Lumpur
Jalan Pahang, 50586 Kuala Lumpur

Email	: ntrc@hkl.moh.gov.my
Tel. (pejabat)	: (603) 26942704/2705
Tel. (faks)	: (603) 26156269
Tel. (bebas tol)	: 1-800-88-9080
Laman sesawang	: www.agiftoflife.gov.my

Risalah ini diterbitkan bertujuan memberi maklumat asas kepada orang ramai mengenai pendermaan organ semasa hidup. Sebagaimana yang telah diperuntukkan di dalam garispanduan Kementerian Kesihatan Malaysia mengenai pendermaan organ semasa hidup tiada kaitan keluarga atau "Unrelated Living Organ Donation: Policy and Procedures", doktor yang bertanggungjawab terhadap penderma perlu memberikan risalah ini kepada individu tersebut untuk dibaca. Namun begitu, komunikasi serta sesi perundingan bersama doktor pakar masih lagi relevan dan penting bagi menerangkan lebih lanjut mengenai risiko dan kelebihan menderma organ. Jika perlu, bantuan dari seorang penterjemah hendaklah diperolehi. Bakal penderma perlu diberikan informasi yang relevan bagi membolehkan penderma membuat keputusan sendiri berdasarkan maklumat yang diberikan.

Risalah diterbitkan oleh Unit Perkhidmatan Transplan, Bahagian Perkembangan Perubatan. Untuk sebarang maklumbalas sila hantarkan emel anda kepada transplantation_unit@moh.gov.my, atau menukar surat dan hantar ke alamat Unit Perkhidmatan Transplan, Aras 5, Blok E1, Kompleks E, Pusat Pentadbiran Kerajaan Persekutuan, 62590 Putrajaya Malaysia.

KUMPULAN KERJA:

Dr Hirman Ismail, Dr Rosnawati Yahya, Datuk Dr Harjit Singh, Datuk Dr Ghazali Ahmad, Dr Wong Hin Seng, Dato' Dr Rohan Malek, Datin Dr Fadhilah Zowyah Lela Yasmin Mansor, Dr Tan Chwee Choon, Matron Jamaliah Kario.

Hakcipta terpelihara. © 2011 Bahagian Perkembangan Perubatan, KKM.



KEMENTERIAN KESIHATAN MALAYSIA
www.moh.gov.my

Appendix 12

Declaration of Conflict of Interest and Confidentiality
(UTAC Members/Technical Advisors)



DECLARATION OF CONFLICT OF INTEREST AND CONFIDENTIALITY

I, hereby accept the appointment as a Member/ Technical Advisor of Unrelated Transplant Approval Committee, case no. for an application of organ transplantation between unrelated individuals, (*name/IC of prospective donor*) and (*name/IC of prospective recipient*). To the best of my knowledge and belief, I am involved in no situation or action that might be regarded as a potential conflict of interest with my duties as a Member/Advisor/Secretariat of this Committee. I will maintain confidentiality of all information relating to this application.

.....
(signature of UTAC Member/ Advisor)

Name :

IC :

MMC no. :

Designation :

Institution :

Appendix 13

Declaration of Conflict of Interest and Confidentiality
(IDAT)



DECLARATION OF CONFLICT OF INTEREST AND CONFIDENTIALITY

I, hereby accept the appointment as a Member of Independent Donor Advocate Team (IDAT) under the Unrelated Transplant Approval Committee, case no. for an application of organ transplantation between unrelated individuals,
(name/IC of prospective donor) and (name/IC of prospective recipient). To the best of my knowledge and belief, I am involved in no situation or action that might be regarded as a potential conflict of interest with my duties as a Member of Independent Donor Advocate Team (IDAT). I will maintain confidentiality of all information relating to this application.

.....
(signature of a Member of IDAT)

Name :

IC :

MMC no. :

Designation :

Institution :

Appendix 14

Format for Case Summary

CASE SUMMARY

Application for Evaluation and Approval of the
Unrelated Transplant Approval Committee (UTAC)

(This case summary is to be prepared by the Secretariat of UTAC for future reference. Relevant contents of discussion in UTAC meeting are to be recorded in the summary section.)

Case no. :

Date of application :

Date of evaluation :

Date of UTAC meeting :

Applicant

Name :

Designation :

Institution :

Prospective recipient

Name :

Nationality :

Race :

Age :

Diagnosis :

Prospective donor

Name :

Nationality :

Race :

Age :

Relationship (if any) :

UTAC members

1.
2.
3.
4.
5.
6.

CASE SUMMARY (UTAC)

Advisors

1.
2.

Independent Donor Advocate Team (IDAT)

1.
2.
3.

Secretariat

1.
2.
3.

Status of application: APPROVED/ DENIED

Summary

Content among others;
.....

Reasons why the case was approved or disapproved,
.....

List down important factors/concerns,
.....

Any conflict or different of opinion between UTAC members,
.....

Any other relevant content of discussion to be recorded.
.....

CASE SUMMARY (UTAC)

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

This case summary was prepared by:

.....
(signature of the Secretariat of UTAC)

Name :

IC :

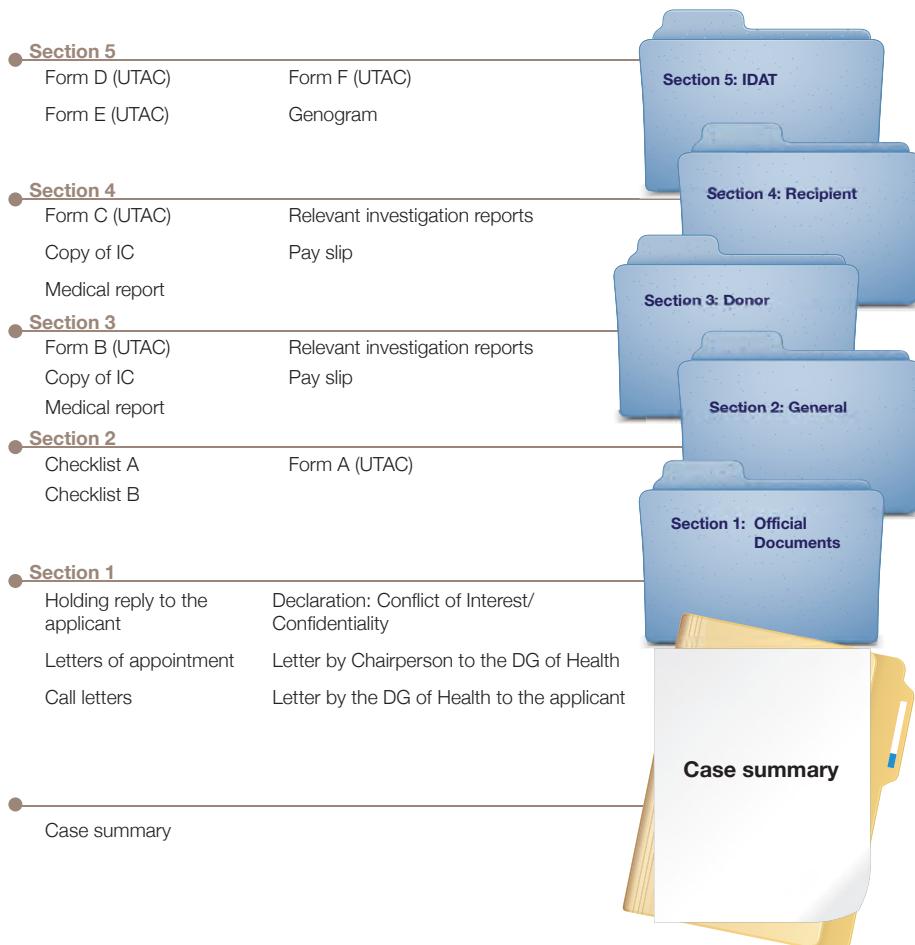
MMC no. :

Appendix 15

Filing System: Arrangement of Documents

FILING SYSTEM: Arrangement of Documents

1. For every UTAC application, a dedicated file or folder has to be prepared by the secretariat. The file shall be categorised as "CONFIDENTIAL" and only privileged persons have the rights to view the documents.
2. Each document shall be given a specific number.
3. All documents shall be orderly arranged as follow (front to back):
 - a. Case summary
 - b. Section 1: Official documents
 - c. Section 2: General
 - d. Section 3: Donor
 - e. Section 4: Recipient
 - f. Section 5: IDAT



* Folders for UTAC members shall be arranged as above but without case summary and section 1.

DRAFTING AND REVIEW COMMITTEE

CONTRIBUTORS

Dr Hirman Ismail

Principal Assistant Director
Transplantation Unit
Medical Development Division
(Main author/ editor)

Dato' Dr S. Noor Ghani

Senior Lecturer
Department of Social and Preventive Medicine
Faculty of Medicine, University Malaya

Datuk Dr Ghazali Ahmad

Consultant Nephrologist
Hospital Kuala Lumpur
(Head of Nephrology Service,
Ministry of Health Malaysia)

Datuk Dr Harjit Singh

Consultant Hepato-biliary Surgeon
Hospital Selayang
(Head of General Surgery Services, Ministry of
Health Malaysia)

Dr Tan Chwee Choon

Consultant Nephrologist
Hospital Tengku Ampuan Rahimah Klang

Dr Rosnawati Yahya

Consultant Nephrologist
Hospital Kuala Lumpur

Datin Dr Fadhilah Zowyah

Lela Yasmin Mansor
Chief Clinical Manager
National Transplant Resource Centre
Hospital Kuala Lumpur

Dato' Dr Rohan Malek

Consultant Urologist
Hospital Selayang
(Head of Urology Service,
Ministry of Health Malaysia)

Dr Wong Hin Seng

Consultant Nephrologist
Hospital Selayang

Mr R.Krishnan

Consultant Hepato-biliary Surgeon
Hospital Selayang

Matron Jamaliah Kario

Senior Transplant Coordinator
National Transplant Resource Centre
Hospital Kuala Lumpur

REVIEW PANEL

Dato' Dr Azmi Shapie

Director
Medical Development Division
Ministry of Health Malaysia

Dr Teng Seng Chong

Senior Deputy Director
Medical Development Division
Ministry of Health Malaysia



For more information on organ donation, log on to www.agiftoflife.gov.my



MINISTRY OF HEALTH MALAYSIA
www.moh.gov.my