MOH/S/IPTK/47.24(TR)

TECHNICAL REPORT

UNDERSTANDING THE VIEWS OF THE MALAYSIAN PUBLIC TOWARDS DECISION MAKING FOR END-OF-LIFE CARE: AN ONLINE STUDY







INSTITUTE FOR HEALTH BEHAVIOURAL RESEARCH
NATIONAL INSTITUTES OF HEALTH
MINISTRY OF HEALTH MALAYSIA



TECHNICAL REPORT

Understanding the Views of the Malaysian Public Towards Decision Making for End-of-Life Care: An Online Study

Institute For Health Behavioural Research
National Institutes Of Health
Ministry Of Health
Malaysia

NMRR-21-233-58532

Copyright © 2023 Institute for Health Behavioural Research, National Institutes of Health, Ministry of Health, Malaysia.

Any questions or comments about this report should be directed to the following;

Principal Investigator, Understanding The Views of Malaysian Public Towards Decision Making for End-Of-Life Care, An Online Study, Institute for Health Behavioural Research, National Institutes of Health.

Disclaimer:

All rights reserved. It is not permitted to reproduce any part of the book's text, illustrations and contents in any form and in any way, whether electronically, photocopy, mechanic, recording or otherwise, except with the written consent of the Ministry of Health Malaysia.

Suggested citation:

Institute for Health Behavioural Research (IHBR), National Institutes of Health, Ministry of Health Malaysia. (2023). Understanding The Views of Malaysian Public Towards Decision Making for End-Of-Life Care, An Online Study.

Printed and distributed by:

Institute for Health Behavioural Research, Blok B3, National Institutes of Health (NIH), No. 1, Jalan Setia Murni U13/52, Seksyen U13, Setia Alam, 40170 Shah Alam, Selangor.

Telephone : +603 3362 7600

Emel : tadbir_iptk@moh.gov.my
URL : https://iptk.moh.gov.my

The use and dissemination of this document are encouraged. However, neither this document nor the reprints may be used for commercial purposes. The views written in this report are solely the authors' views. They do not necessarily represent the views of other researchers or the views or policies of the Malaysian Ministry of Health.

TECHNICAL ADVISORS

Dr. Manimaran a/l Krishnan Director, Institute for Health Behavioural Research (IHBR) Ministry of Health Malaysia

Dr. Richard Lim Boon Leong Palliative Medicine Physician & Head of Palliative Unit Hospital Selayang

Dr. Sylvia McCarthy HOSPIS Malaysia

Associate Prof. Dr. Lai Siew Mei Pauline Universiti Malaya

Lim Mun Kit Monash University, Malaysia

LEAD AUTHOR

Sheikh Shafizal bin Sheikh Ilman, Institute for Health Behavioural Research (IHBR), National Institutes of Health Ministry of Health Malaysia

AUTHORS

- 1. Nadia Hani Jahaya Institute for Health Behavioural Research (IHBR), Ministry of Health Malaysia
- 2. Nurashma Juatan Institute for Health Behavioural Research (IHBR), Ministry of Health Malaysia
- 3. Zaikiah Mohd Zin Institute for Health Behavioural Research (IHBR), Ministry of Health Malaysia
- 4. Abu Bakar Rahman Institute for Health Behavioural Research (IHBR), Ministry of Health Malaysia
- 5. Dr Cindy Teoh Cy Oun Hospital Selayang, Ministry of Health Malaysia
- 6. Dr Woon Yuan Liang Institute of Clinical Research, Ministry of Health Malaysia
- 7. Dr Mark Cheong Wing Loong Monash University, Malaysia

Acknowledgement:

The authors would like to thank the Director-General of Health and Deputy-General of Health (Research and Technical Support), Ministry of Health Malaysia, for granting permission to publish this report. Our gratitude goes to Dr. Manimaran Krishan, Director of the Institute for Health Behavioural Research, for his comment and suggestion to improve the report. The successful completion of this report was made possible through the significant contributions and active participation of numerous organizations and individuals who were involved in this study. Their invaluable efforts, insights, and dedication have played a crucial role in shaping the outcomes of this research. We extend our heartfelt gratitude and sincere appreciation for their unwavering support and commitment throughout the process. We also thank the Malaysians for answering the questionnaire and making this study a success.

REVIEWERS

Dr. Lam Chee Loong Medical Lecturer Department of Medicine Faculty of Medicine University Malaya

Gunasundari a/p Marimuthu Health Education Officer Institute for Health Behavioural Research (IHBR) Ministry of Health Malaysia

Norbaidurah Ithnain Health Education Officer Institute for Health Behavioural Research (IHBR) Ministry of Health Malaysia

Komathi Perialathan Health Education Officer Institute for Health Behavioural Research (IHBR) Ministry of Health Malaysia

Logeswary Krisnan Health Education Officer Institute for Health Behavioural Research (IHBR) Ministry of Health Malaysia

DIRECTOR'S NOTE



Advance Care Planning (ACP) is a process that enables adults and health to understand and share their personal values, lifestyle goals and preferences related to future medical care. Regardless of the clinical scenario, ACP must be proactive, timely and integrated into routine care.

To date, many countries have adopted advance care planning as part of their health services. Thus, it is time for our country to take the same steps to improve its healthcare components. Although there are many benefits to the implementation of this service, the most important aspect is to take into account Malaysia's views on the matter.

Recognizing its importance, the Institute has taken the initiative to carry out this study to explore Malaysian views on decision-making for end-of-life care. Malaysian awareness, attitude acceptance and intention towards decision-making for end-of-life care play an important role in respecting the patient's wishes, improving their quality of care and strengthening the bond between family and friends to walk them through to the next stage of life.

Therefore, I hope that the publication of this technical report will help the Ministry of Health establish a baseline to serve as a reference source for better understanding Malaysian decision-making on end-of-life care.

Thank You

Dr. Manimaran Krishnan

Director Institute For Health Behavioural Research (IHBR) National Institutes of Health

Ministry of Health Malaysia

TABLE OF CONTENTS

1.0	Introduction				
	1.1	Global ACP Implementation	1		
	1.2	ACP Implementation in Malaysia	2		
	1.3	Problem Statement and Justification of Study	3		
	1.4	Research Question	3		
	1.5	Objective	4		
		1.5.1 General Objective	4		
		1.5.2 Specific Objective	4		
	1.6	Significance of the Study	4		
	1.7	Conceptual and Operational Definition	4		
2.0	Methodology				
	2.1	Study Population	6		
	2.2	Study Design	6		
	2.3	Sampling Calculation	6		
	2.4	Study Instrument	7		
	2.5	Instrument Validation	8		
	2.6	Data Collection Procedure	8		
	2.7	Data Analysis	8		
	2.8	Ethical Approval	9		
3.0	Results				
	3.1	Respondents by State	10		
	3.2	Sociodemographic Characteristic	10		
	3.3	Self-Perceived Health Status and Current Medical Condition	12		
	3.4	Awareness and Source of Information About ACP	13		
		3.4.1 Ever Heard About ACP	13		
		3.4.2 Ever Knew About ACP	14		
	3.5	Views Towards Provision and Usefulness of ACP Services	15		
		In Health Care Facilities			
	3.6	Past Experience in Health-Related Events	16		
	3.7	Acceptance on ACP	16		
	3.8	Perceived Importance of ACP Discussion While Healthy	20		

	3.9	Intention to Have ACP Discussion		20	
	3.10	Preferred Elements in ACP (Procedures, Docur	nentations,	21	
		Choice of Decision Makers)			
		3.10.1 Preferred Clinical & Treatment Procedu	ures to Be	21	
		Included in The ACP Discussion			
		3.10.2 Documentation of Records		22	
		3.10.3 Appointing of Decision Maker		22	
4.0	Discu	ussion		23	
5.0	Limit	tation		26	
6.0	Conc	clusion		26	
References					
Appe	endix:	Questionnaire			
Appen	Appendix 1: Questionnaire				
Appendix 2: Ethical Approval Letter					
Appendix 3: Participant Information Sheet					
Appendix 4: Participant Information Sheet (BM Version)					

List of Figures

Figure 1	: Ever Heard of ACP	13
Figure 2	: ACP Should Be Made Available in Healthcare Facilities	15
Figure 3	: Usefulness Of ACP Services In Health Care Facilities	15
Figure 4	: Respondent Acceptance of ACP	17
Figure 5	: Importance of ACP Discussion When Respondents Are Still Healthy	20
Figure 6	: Method of ACP Documentation of Records	22
Figure 7	: The Preferred Decision Maker If the Respondent Is Unable to	22
	Speak for Themselves	
List of	Tables	
Table 1	: Conceptual and Operational Definition	5
Table 2	: Sample Size Calculation	6
Table 3	: Evidence Table for ACP Questionnaire	7
Table 4	: Number of Respondents by the State in Malaysia	10
Table 5	: Sociodemographic Characteristics of The Respondents	11
Table 6	: Respondents' Self Rated Health Status	12
Table 7	: Ever Heard of ACP Based on Different Sociodemographic Characteristics	13
Table 8	: Soruces of Information About ACP Among Those Who Knew	14
Table 9	: Respondents Answers Based on Their Past Experience of Related Events	16
Table 10	: Respondents' Reasons for Saying YES To Expressing	18
	Treatment Preferences	
Table 11	: Respondents' Reasons for Saying NO To Expressing	19
	Treatment Preferences	
Table 12	: Intend To Have ACP Discussion in The Future	20
Tabel 13	: Does Anyone Encourage the Respondents to Express Their	21
	Preferences For Future Medical Care in Case They Become Very III	
Table 14	: Element to Discuss in ACP If Incapable of Making a Decision	21

