

UNIVERSITI TEKNOLOGI MARA

**INFORMED CONSENT APPROACH
IN MALAYSIAN BIOBANKING FOR
RESEARCH PURPOSES AND ITS
ETHICAL CHALLENGES**

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MSc

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AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the regulations of Universiti Teknologi MARA. It is original and is the results of my own work, unless otherwise indicated or acknowledged as referenced work. This dissertation has not been submitted to any other academic institution or non-academic institution for any degree or qualification.

I, hereby, acknowledge that I have been supplied with the Academic Rules and Regulations for Post Graduate, Universiti Teknologi MARA, regulating the conduct of my study and research.

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ABSTRACT

In biobanking, valid informed consent is crucial to protect participants' autonomy in relation to the use of their biological samples and their associated data for future research. However, traditional model of informed consent may not be adequate for this purpose as future research is yet to be determined. Consequently, few types of modified informed consent models (broad, dynamic and meta consent) have been proposed by bioethics scholars to address this issue. Capturing the differences between these types would give a better understanding in recommending which type of the consent model provides better autonomy protection in the future. Despite several biobanks already established in Malaysia, little is known about the informed consent approach in biobanking research and its ethical challenges. This study aims to identify the informed consent approach in the Malaysian biobanking and its ethical challenges. This study also aims to explore the differences in the modified informed consent models in protecting participants' autonomy and propose a better approach. In depth interview with the informants found that broad consent is mainly used for research purposes and comes with five major ethical challenges. Using systematic review method this study addressed five significant differences in the consent models discussed and propose that dynamic consent has a better approach. Although dynamic consent would have a better approach, its implementation in the Malaysian context may have its own challenges. This study found that there is lack of understanding among the researchers on the ethical, legal and social aspect of biobanking in Malaysia.

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TABLE OF CONTENT

	Page
CONFIRMATION BY PANEL OF EXAMINERS	I
AUTHOR'S DECLARATION	II
ABSTRACT	iii
ACKNOWLEDGEMENT	iv
TABLE OF CONTENT	v
LIST OF TABLES	ix
LIST OF FIGURES	x
CHAPTER ONE: INTRODUCTION	1
1.1 Introduction	1
1.2 Background of the Study	1
1.3 Problem Statement	2
1.4 Research Questions	4
1.5 Research Objectives	4
1.6 Benefit of Research	4
1.7 Significance of Research	5
1.8 Limitation of Research	5
1.9 Organisation of the Thesis	5
CHAPTER TWO: LITERATURE REVIEW	7
2.1 Introduction	7
2.2 Definition and History of Informed Consent in Medical Research	7
2.2.1 Definition of Informed Consent	7
2.2.2 History of Informed Consent in Medical Research	8
2.2.2.1 The Nuremberg Code	9