

TECHNICAL REPORT

UNDERLYING PHENOMENA FOR CANCER DELAYS IN MALAYSIA: PATIENT PERSPECTIVE (UNDERPHEN-CANCER)

(NMRR- 19-3198-51788)

INSTITUTE FOR HEALTH BEHAVIOURAL RESEARCH,
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Institut Penyelidikan Tingkahlaku Kesihatan

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DEDICATION

This study is devoted by the research team to the accomplishment of our objective(s). We anticipate that the findings of this study will assist healthcare providers in improving current flow and patients in improving their quality of life.

MESSAGE FROM THE DIRECTOR



It is gratitude for the opportunity to deliver this technical report as an official publication of Institute for Health Behavioural Research (IHBR). Congratulations to a highly devoted team for their dedication and commitment throughout this research endeavour from its inception till its publication. Their continues effort and hard work enabled this research and report to be possible. The ultimate goal of this study is to explore the delays faced by cancer patients from the start of their symptoms to the treatment they received – focussing solely on their perspectives. This information is vital in providing healthcare providers what do patients experience and how they perceive the services they received in order to take in comments and make improvements.

I believe the report will give a concise impression from the perspectives of different levels of care and the process that can be made better.

Thank you.

A handwritten signature in black ink, appearing to read 'Dr. Manimaran Krishnan'.

Dr. Manimaran Krishnan
Director of Institute for Health


ACKNOWLEDGEMENT

First and foremost, praises and thanks to the Almighty God, for His showers and blessings throughout the completion of the technical report on Underlying Phenomena for Cancer Delays in Malaysia: Patient Perspective (UNDERPHEN-CANCER).

The research team would like to extend our utmost appreciation to the Director General of Health for the permission to have this report published. Special thanks to Dr Manimaran Krishnan, the Director of Institute for Health Behavioural Research, for his vision and support that resulted in this report. This report was also greatly assisted by the contributions and participations made by the many bodies and individuals in both the health authorities and patients involved in this study. Their contributions are sincerely appreciated and greatly acknowledged.

Last but not least, a special thanks to the research team members for all the effort and determination in producing this report. This is the result of all the hard work and challenges we have been through together.

May God richly bless you all.



Dr Mohammad Zabri Johari
Principal Investigator of the study

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Figure 2: Cancer with female only recruitment

Figure 3: Recruitment for cancers that affect both male and females

Figure 4: Analysis Model for delay causes

LIST OF ABBREVIATIONS

ACRONYM	DESCRIPTION
UNDERPHEN	Underlying Phenomena for Cancer Delays in Malaysia: Patient Perspective
NSP-CCP	National Strategic Plan for Cancer Control and Prevention
WHO	World Health Organization
SDG	Social and Development Goals
UN	United Nation
NCCP	National Cancer Control Program
NCD	non-communicable disease
LMIC	low- to middle-income country
MySCan	Malaysian Study on Cancer Survival
UK	United Kingdom
CRC	Clinical Research Centre
IKN	Institut Kanser Negara
HKL	Hospital Kuala Lumpur
HTJ	Hospital Tuanku Jaafar
HQEI	Hospital Queen Elizabeth II
HWKL	Hospital Wanita dan Kanak-Kanak Likas
B40	Bottom 40%
M40	Middle 40%
CSM	Common-sense Self-regulation Model
MREC	Medical Review & Ethics Committee
ICH	International Conference for Harmonisation
IDI	In-depth Interview
KOSPEN	Komuniti Sihat Pembina Negara
TCM	Traditional Complimentary Medicine
MCO	Movement Control Order
ENT	Ear, nose and throat
HCP	Healthcare provider
COVID	Coronavirus disease

EXECUTIVE SUMMARY

The UNDERPHEN Study was consigned by the Disease Control Division at Ministry of Health as part of the National Strategic Plan for Cancer Control and Prevention (NSP-CCP) documents to answer the World Health Organization's (WHO) Social and Development Goals (SDG).

This project was fully funded by the Ministry of Health Malaysia, project code NMRR-19-862-46635. This study obtained ethical clearance from The Ministry of Health Malaysia – KKM/ NIHSEC/P19-1453(7) and was carried out in 1 year duration.

Designed as a qualitative study, the outcomes of the study intended to understand the experiences and feedback from the patient's point of view as increasing numbers of cancer is detected, the challenges of services provision is needed to be addressed.

This report is written to provide an overview of the process involved in study in revealing the findings of data collection conducted. Findings included delays in the various stages of cancer through the health services in the perspectives of the participants. Delays found are type specific and varies in stages of delay are subject to cancer type.

The main delays are in the treatment phase and the major aspects are diagnosis and treatment errors, miscommunication between patient and provider, limitations in access to health providers and services, the patient's internal issues that in the end led to an issue of distrust. These findings are integral to understand the struggles and how services can be improved.

This report is meant for policy makers, stakeholders, funding agencies and those who are interested in the study topic. The findings will detail the reasons of why delay occurs in cancer treatment and this will provide an insight on how to tackle the delays on the implementers side via modification of existing guidelines and practices.

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