



CASE STUDY FROM MALAYSIA - CANCER INFORMATION SERVICE (CIS), NCSM, KUALA LUMPUR, MALAYSIA



## History

- The president of NCSM, Dr Saunthari went for a Cancer Information Support Service Workshop in Geneva, Switzerland, in 2008
- She was inspired to start a dedicated line in Malaysia in order to support the cancer journey of Malaysians by empowering patients with strength and knowledge to face cancer
- She and a few representatives from NCSM went for a training workshop with Cancer Council Victoria, Australia and CRUK to understand and learn about cancer information support and ways to implement it in the country

## Background



- Accurate provision of health information remains a public health challenge<sup>1</sup>.
- Patient with poor levels health information are associated strongly with poor health decision-making, especially in patient with different chronic disease such as cancer<sup>1</sup>.
- In Malaysia, evidence shows that up to 20% of patients forego cancer treatment upon diagnosis; or opt for alternative, non-proven therapies<sup>2,3</sup>.
- The National Cancer Society of Malaysia (NCSM) established a (CIS) system in 2016, which is a dedicated information service staffed by healthcare professionals (HCPs) and offering an interactive mode of communication via a toll-free hotline, email and social media about all cancer aspects to patients and caregivers.

References:

<sup>1.</sup> Koay K. Schofield P, Jefford M (2012). Importance of health literacy in oncology. Asia Pacific Journal of Clinical Oncology, 8(1), 14-23.

<sup>2.</sup> Mohd Mujar NM, Dahlui M, Emran NA, et al. (2017). Complementary and alternative medicine (CAM) use and delays in presentation and diagnosis of breast cancer patients in public hospitals in Malaysia. PLoS One. 12:e0176394.

<sup>3.</sup> Chan CM, Wan Ahma WA, MD Yusof M, Ho DF, Krupat E. (2015). Prevalence and characteristics associated with default of treatment and follow-up in patients with cancer. European Journal of Cancer Care, 24(6): 938-44.



## CANCER INFORMATION SERVICE (CIS) OPERATIONAL



## **1800-88-1000** help@cancer.org.my

The National Cancer Society of Malaysia (NCSM) established a (CIS) system in 2016, which is a dedicated information service staffed by healthcare professionals (HCPs) and offering an interactive mode of communication via a toll-free hotline, email and social media about all cancer aspects to patients and caregivers.

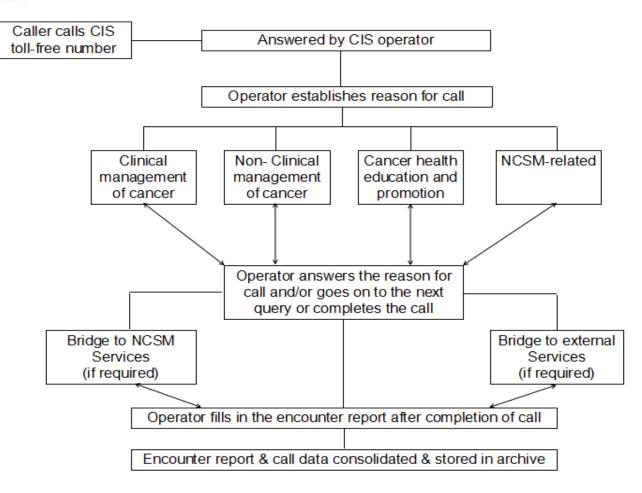
- Toll-free Cancer Helpline
- Operated by nurses (including oncology nurses)
- Free, multilingual and confidential service

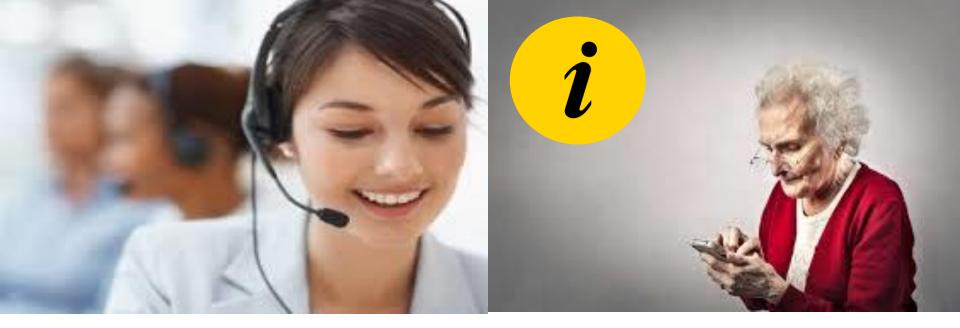


## Why a Cancer Helpline? To address the lack of professional and accurate cancer information and support services



## **CIS Workflow**





We provide **information** on cancer as well as **support** services to cancer patients; their families and friends; healthcare professionals and the general public.

CIS nurses provide oneon-one interaction.

## **CIS SUPPORTS**



**Respect** and **support** to **patients** and to their relationship with their doctor(s)/healthcare professional(s)



## CIS nurses do <u>NOT</u> dispense medical advice.

- Information provided by CIS is general in nature and does <u>not</u> replace the advise or consultation with a physician.
- When appropriate, a CIS nurse will inform a user of options for seeking a second opinion.

National Cancer Society Malaysia





#### Service is **non-judgemental** Enquiries are kept private and confidential



## **CIS is TAILORED**

- **Dedicated, direct** helpline (not a general line)
- Knowledge base obtained from leading cancer organisations worldwide



Tailored to suit Malaysian society

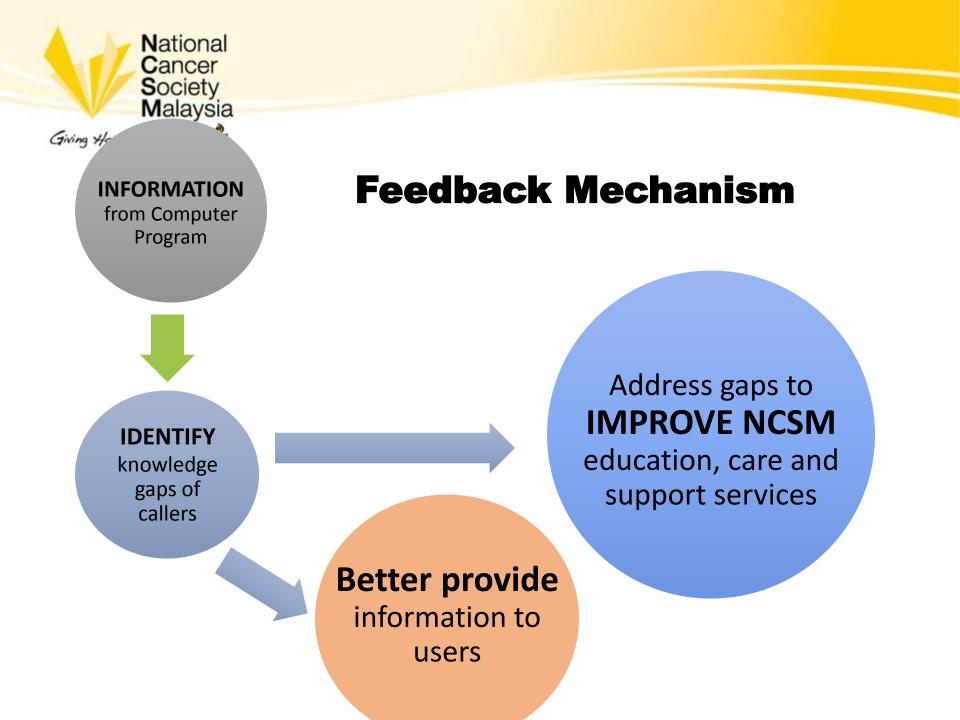
• Uses international guidelines set by the International Union for Cancer Control (UICC) and worldwide organisations (e.g. Cancer Research UK, American Cancer Society)

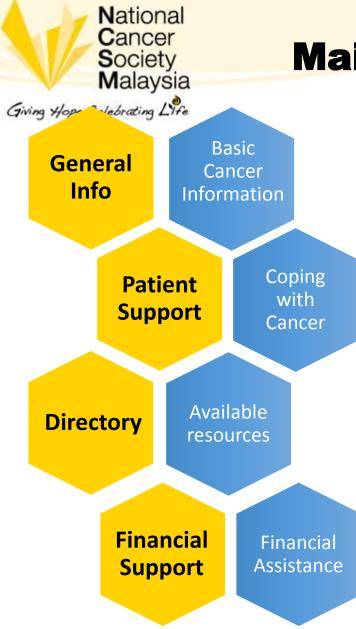


# Specialised computer program



RECORDS **NOTES** that can be used for reference RECORDS AND CAPTURES major concerns of callers





#### **Main Areas Covered**

Types of cancer, treatments Side effects

Emotional and nutritional support Survivorship

Hospitals, home nursing, palliative care, support groups

Assistance navigating services such as insurance, EPF, SOCSO, religious bodies, NGO funds, government



## CHALLENGES

- Setting Up System
- -technical technicalities(changing providers)
- Toll-free service provision
  -Vendor management
- Sustainable Funding
  Increasing usage of service





## STRATEGIES FOR IMPROVEMENT

Giving Hope Celebrating Life

- Joint-marketing -PACED campaign Promote at all speaking events -200 events a year
- marketing campaign to clinicians
- i) through Medical Association to all GPs

ii) F2F campaign in Klang Valley first phase



## Thank you



# 1800-88-1000 help@cancer.org.my

CIS operates Monday to Friday 8.30am – 4.30pm

www.cancer.org.my