

Patient Engagement
The role of breast cancer patient in breast cancer control

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Patient Engagement

The role of breast cancer patient in breast cancer control

- Introduction – Then and Now
- Status of the patient
- Peer support & peer navigation
- Lived experience and survivorship
- Clinical trials and research
- Advocacy
- Planning services
- Conclusion

The role of breast cancer patient in cancer control Then and Now

Then

Historical perspective

Strong top down approach

Now

Patients as equal partners in the HC system

Shared decision making

Open communication – ability to ask questions without intimidation

Patient Engagement

The role of breast cancer patient in breast cancer control

Role of the Individual with Cancer

Victim -----> Patient -----> Consumer -----> Survivorship - focus on self & survival

- In need of treatment, support, navigation and information

-----> Volunteer – focus on enabling others

- Offer support, education and information

-----> Advocate – seeking change and improvement

- Influence policies on cancer control

Peer Support

Psychosocial, health literacy, logistics, financial

Reach to Recovery peer support: A woman who has lived through breast cancer and gives freely of her time to help another woman facing the same experience is a valuable source of support to improve QoL for the patient and her family through a wide range of services offered worldwide.

www.reachtorecoveryinternational.org

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Training and annual recertification is essential.



Peer Navigation (training is important)

Helps patient move through the cancer care system

Peer Navigation

(Patient Navigation was started by Harold Freeman in 1990)

Peer navigator can:

- Give one-on-one assistance to patients, families and caregivers to overcome barriers.
- Identify needs together with the patient and responds to concerns.
- Give psychosocial support, information and links patient to service providers and agencies
- Help patient with language translation and document completion.

Objectives: Increase patient's capacity for knowledge and support, meet identified needs, reduce anxiety, overcome barriers, access clinical and psychosocial services, improve coordination among individual services at touch points.

The importance of the Lived Experience and Survivorship

Narrating or sharing personal experience on understanding the disease experience

- public education, education of HCP
- New patient and family education and support - reduce fears, address concerns, issues re mortality, overcoming barriers
- Influencing policy – the voice of the patient can be powerful in informing HCP and policy makers about challenges and suggesting solutions.
- Addressing social stigma – importance of dignity and respect, dispelling myths

Just because the course of the disease is difficult to predict there are too many assumptions and negative social attitudes

Patient engagement in Research & Clinical Trials

Meaningful patient input into the clinical trial processes

Patient involvement leads to empowerment and enhances the quality of research – formation of a Patient Board involving patients and researchers.

Clinical trials *with or for* patients?

Patient centred approach can enable the patient to have an active role in health care systems

- Addresses needs and values of patients
- Increase participation of patients in clinical trials
- Improve QoL during the treatment

Patient led evidence: Advocacy Breast Cancer Foundation NZ

Petitioning for free GP visits for those with Advanced Breast Cancer

Sep 2018: *"I'm still here", Insights into living – and dying – with ABC in New Zealand*

Report: ABC patients' challenges to manage symptoms, reduced QoL, and increased premature mortality, and financial toxicity. GP costs created financial toxicity when patients no longer have regular hospital appointments; inability to afford appointments means patients don't get the symptom relief they need.

BCFNZ presented a petition calling for free GP visits for ABC patient, which is currently with the Health Select Committee.

Patient led evidence: Advocacy

Breast Cancer Foundation NZ

Jan 2019: released "*I'm still here*" BCFNZ invited Dr Fatima Cardoso, President of ABC Global Alliance to share her knowledge in NZ "*From passenger to co-driver*".

Audience included patients, doctors, government: importance of the relationship patients need to have with their oncologist and how they can take a front seat in their ABC care.

BCFNZ also secured public support to advocate to the government that ABC patients in NZ need funding for all the drugs listed in ESMO guidelines for the treatment of their disease.

BCFNZ presented a petition to the Health Select Committee for free GP visits for ABC patients.

March 2020, Pharmac NZ announced it was funding Ibrance ([palbociclib](#)), which previously costed \$6000 for a month's supply of the drug.

Advocacy in access to cancer care

TAC wrote to PM

Zero-rated GST for cancer drugs

October 2015

← Together Against Cancer Association Malaysia

PAGE ACTIVITY INSIGHTS

TAC - Together Against Cancer Association Malaysia 🇲🇾 feeling excited
23 Oct at 5:38pm · 🌐

Zero rated GST on all types of controlled medicines under Groups A, B, ... on 95 over the counter medication for 30 illnesses, including CANCER #Bajet2016 **TAC - Together Against Cancer Association Malaysia**

ASTRO AWAMAN LANGSUNG
PERTAMAHON RTM

GST

PERTAMBAHAN DARIPADA
4,215
JENIS UBAT KEPADA

8,630
JENIS UBAT

Karan Johar kini 'millionaire' di Instagram

4 likes 504 views

Like Comment Share

6,317 people saw this post

Boost Post

TAC - Together Against Cancer Association Malaysia 🇲🇾
20 Sep at 10:55pm · 🌐

You may visit our webpage @ tacmalaysia.ucoz.com for more

Elevating the Voice of Cancer Patients

TIME FOR ACTION AGAINST CANCER



Together Against Cancer (TAC) aims to ensure that all Malaysians affected by cancer are empowered by knowledge, strengthened by action and sustained by the community.

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Together Against Cancer Association Malaysia (TAC)
Persatuan Advokasi Kesihatan Kanser Malaysia

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The patient's voice in planning services

Clinical Practice Guidelines: Management of
Breast Cancer (2nd edition)

Ministry of Health Malaysia

Nov 2010



Optimising healthcare delivery-BHGI

- **BASIC LEVEL:** Core resources or fundamental services necessary for any breast health care system to function. Typically applied in a single clinical interaction.
- **LIMITED LEVEL:** Resources or services are attainable with limited financial means and modest infrastructure and produce major improvements in outcome such as survival.
- **ENHANCED LEVEL:** Resources or services that are optional but important, because they increase the number and quality of therapeutic options and patient choice and improve outcomes.
- **MAXIMAL LEVEL:** Services used in some high resource settings that have *lower priority* on the basis of extreme cost and/or impracticality.

ABC GLOBAL CHARTER

10 goals for the next 10 years

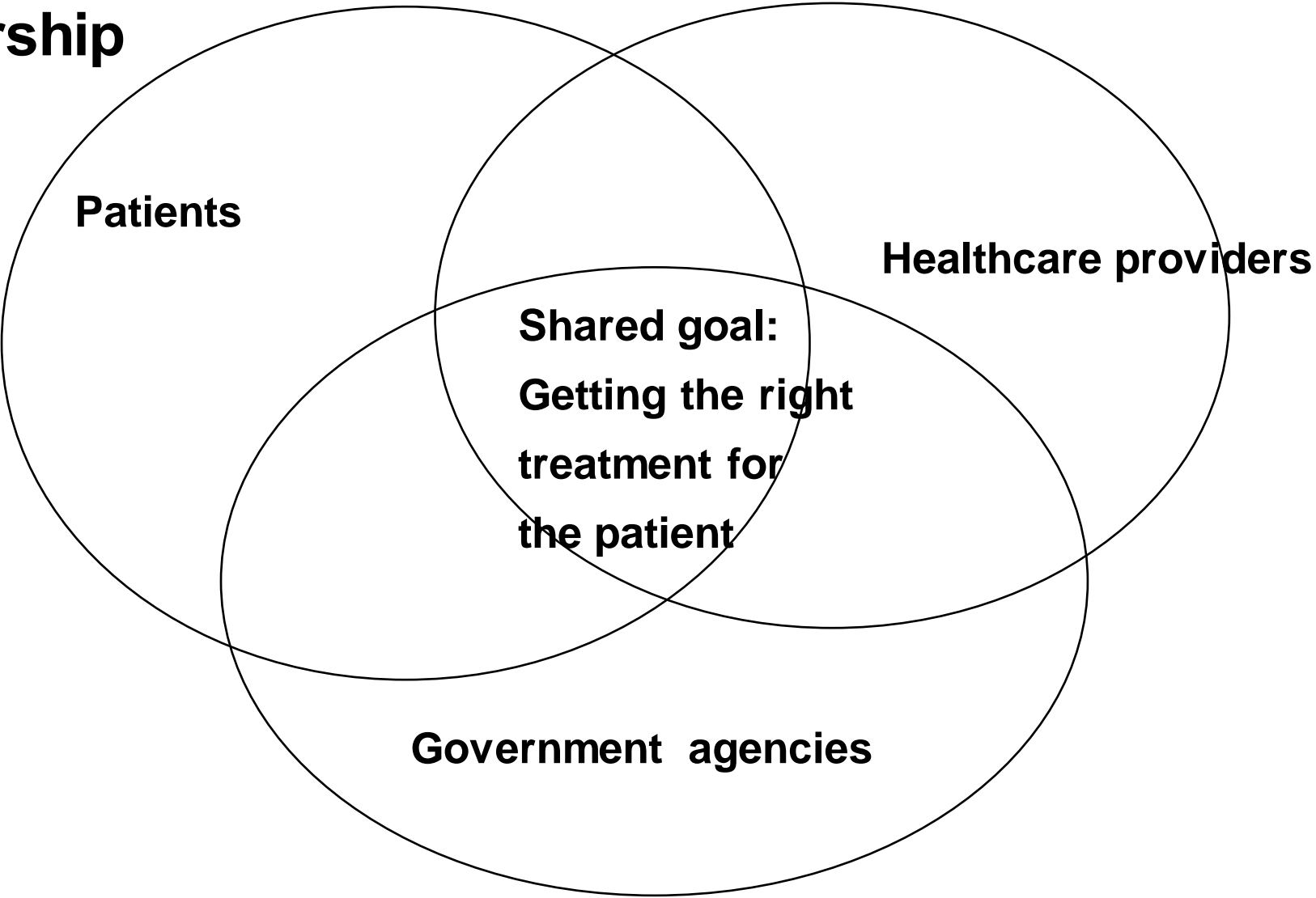


The ABC Global Charter has been developed to address the most urgent and actionable gaps in treatment and care of patients with advanced breast cancer (ABC) to ultimately improve and extend their lives.

- 1 HELP PATIENTS WITH ABC LIVE LONGER BY DOUBLING ABC MEDIAN OVERALL SURVIVAL BY 2025**
- 2 ENHANCE OUR UNDERSTANDING ABOUT ABC BY INCREASING THE COLLECTION OF HIGH QUALITY DATA**
- 3 IMPROVE THE QUALITY OF LIFE (QOL) OF PATIENTS WITH ABC**
- ENSURE THAT ALL PATIENTS WITH ABC RECEIVE THE BEST POSSIBLE TREATMENT AND CARE BY INCREASING AVAILABILITY OF ACCESS TO CARE FROM A MULTIDISCIPLINARY TEAM
- 5 IMPROVE COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS (HCP) AND PATIENTS WITH ABC THROUGH THE PROVISION OF COMMUNICATION SKILLS TRAINING FOR HCPS**
- 6 MEET THE INFORMATIONAL NEEDS OF PATIENTS WITH ABC BY USING EASY TO UNDERSTAND, ACCURATE AND UP-TO-DATE INFORMATION MATERIALS AND RESOURCES**
- 7 ENSURE THAT PATIENTS WITH ABC ARE MADE AWARE OF AND ARE REFERRED TO NON-CLINICAL SUPPORT SERVICES**
- 8 COUNTERACT THE STIGMA AND ISOLATION ASSOCIATED WITH LIVING WITH ABC BY INCREASING PUBLIC UNDERSTANDING OF THE CONDITION**
- ENSURE THAT PATIENTS WITH ABC HAVE ACCESS TO TREATMENT REGARDLESS OF THEIR ABILITY TO PAY
- 10 HELP PATIENTS WITH ABC CONTINUE TO WORK BY IMPLEMENTING LEGISLATION THAT PROTECTS THEIR RIGHTS TO WORK AND ENSURE FLEXIBLE AND ACCOMMODATING WORKPLACE ENVIRONMENTS**

Conclusion

Partnership



Patients

Healthcare providers

**Shared goal:
Getting the right
treatment for
the patient**

Government agencies

Thank you

Terima kasih

Arkoun

Cảm ơn bạn

Salamat

Khob Chai

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Obrigadu

Kyayjuutainpartaal ကျေးဇူးတင်ပါတယ်