

**Together Against Cancer Malaysia**  
**Association for Cancer Advocacy (ACAM)**

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### **Background and rationale**

NGOs play an increasingly important and often unique role in healthcare. Many NGOs are patient support groups. They provide practical help to patients in the care and treatment of their illnesses, they help patients navigate our complex and fragmented health system, and uniquely they educate and support patients in coping with the emotional and social effects of their medical problems outside the formal health system. Some NGOs are even directly involved in the financing and delivery of specific health services, most famously the NKF and other NGOs which together provide dialysis services to about 8000 patients (25% of the 32,000 patients) in Malaysia.

The actions of individual patients, healthcare providers and NGOs however must occur within the ambit of the configuration and functioning of our health system (how health services in Malaysia are governed, financed, resourced and delivered), which constrain our actions and opportunities, and through which will ultimately impact on our health and lives. But the health system in any country is man-made; its design and functioning are determined largely by deliberate public policy decisions. All citizens ought to have a say in these policy decisions, but the reality is that policy makers such as politicians, government officers, regulators and payers will invariably have the biggest say, and there is little guarantee that they would necessarily decide in our best interest. The policy process in Malaysia is often opaque and it is difficult to hold policy makers to account (except through the electoral process which in Malaysia is far removed from health concerns). Civil society must therefore not abnegate from its obligation to provide the critical and necessary inputs to and oversight of the policy making process to ensure our health policy serves everybody's interest.

Health policy by its nature is all encompassing, it affects everybody. Health policy decisions often entail the spending of huge amount of everybody's monies (whether paid by our taxes, employee benefits, premiums etc) and the policy decisions crucially determine everybody's access to needed care (eg immunization for all, access to dialysis or cancer drugs etc). Yet it is practically impossible for citizens to individually engage policy makers to affect our health policy. Collective action is necessary. There is a need for a national body to galvanize the commitment of all citizens to protect and enhance our rights to quality healthcare in Malaysia.

The TAC is thus conceived through the joint efforts of patients, survivors (of life threatening diseases), carers and concerned professionals. It is motivated to provide a

unified voice for all current and future patients, to improve access to high quality healthcare in Malaysia through health policy and legislative reforms.

### **Proposed Aims of TAC**

The Association is established to

1. Foster the development of cancer advocacy as a crucial tool for positive change in cancer healthcare in Malaysia
2. Take concerted action as a civil society group in matters affecting our health system, and to make representations to the Government, regulators, payers and other relevant authorities on the effect of cancer health policy that government and other policy makers may introduce from time to time
3. Strengthen the capacity for scientifically sound and ethically proper cancer health advocacy
4. Further the development of training and continuing education for cancer health advocates and other interested health NGOs.
5. Promote a closer relationship and an improved understanding among cancer health advocates and health NGOs.
6. Drive the introduction of new best practices and technologies in cancer healthcare and improve cancer patient access to these healthcare through health policy reforms.
7. Take any lawful action incidental or conducive to the attainment of the objective of the Association

### **Proposed activities of TAC**

The activities of the Association shall include:

- Develop positions on specific cancer health issues that TAC will advocate
- Undertake research and collect information relating to the specific cancer health issues to substantiate the evidence base of TAC's position.
- Disseminate information on TAC's positions and actions through mass media, public forum, awareness campaign, report publication, peer-to-peer communication, electronic newsletter and other web resources.
- Engage and conduct dialogue session with policy makers and relevant government agency with responsibility for particular cancer health policy matter.
- Training programs on cancer health advocacy

### **Membership rules**

- Full Membership is open to all citizens of Malaysia
- Application for membership shall be proposed and seconded by two existing members
- An entrance fee of RM 10, Life membership of RM25, and annual subscription of RM 20

**Inaugural meeting**

This shall be called for the formation of the Association on

Date: **Tuesday 23 June 2015** 12pm (Noon) to 2pm

Venue: **Conference room, Department of Surgery, Faculty of Medicine, University of Malaya**

*Agenda:*

1. Discussion and agree on the formation of the Association.
2. Approve the name of the association.
3. Approve the place of business (address) to be registered.
4. Appoint Members of the Pro-tem Committee for handling the registration of the association.
5. Approve the constitution and rules of the association to be registered.
6. Appoint secretariat to undertake registration, develop organizational resources and operate the Association day-today.

A record of the proceedings of the inaugural meeting (minutes of the meeting) of the Association as well as the resolutions as enunciated above shall be made.