

COMMENTARY

Building Partnership in Oral Cancer Research in a Developing Country - Processes and Barriers

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Abstract

Background: The rising burden of cancer in the developing world calls for a re-evaluation of the treatment strategies employed to improve patient management, early detection and understanding of the disease. There is thus an increasing demand for interdisciplinary research that integrates two or more disciplines of what may seemed to be highly unrelated and yet very much needed as strategies for success in research. This paper intends to present the processes and barriers faced in building partnerships in oral cancer research in a developing country. **Methods:** A case study was undertaken in a developing country (Malaysia) to assess the strengths and weaknesses of the situation leading to the formation of a multidisciplinary research partnership in oral cancer. Following the formalization of the partnership, further evaluation was undertaken to identify measures that can assist in sustaining the partnership. **Results:** The group identifies its strength as the existence of academia, research-intensive NGOs and good networking of clinicians via the existence of the government's network of healthcare provider system who are the policy makers. The major weaknesses identified are the competing interest between academia and NGOs to justify their existence due to the lack of funding sources and well trained human resource. **Conclusions:** With the growing partnership, the collaborative group recognizes the need to develop standard operating procedures (SOPs) and guidelines for the sharing and usage of resources in order to safeguard the interest of the original partners while also attending to the needs of the new partners.

Key Words: Oral cancer - partnership - team science - Malaysia

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Background

Oral cancer incidence and mortality rates have either been stable or increasing in the last four decades, with sharp increases seen in Germany, Denmark, Scotland, Central and Eastern Europe, Japan, Australia, New Zealand and among the non-Caucasians in the US (Stewart and Kleihues, 2003). It is noted that the incidence of oral cancer is higher in developing countries as compared to developed countries for both sexes. The highest incidence for males and females was reported to be in the South Asia region with 12.7 and 8.3 per 100,000, respectively (Parkin et al., 2005).

Traditionally, oral cancer management has been limited to specific disciplines but this has been proven to be ineffective because the aetiology of oral cancer is multifactorial. Thus the management of oral cancer nowadays involves experts across many disciplines. Similarly,

understanding the natural history of the disease and its consequences requires a multi and interdisciplinary research approach. Sellers et al (2006) described this as a research evolution towards 'team science'. The increasing demand for interdisciplinary research that integrates two or more disciplines of what may seemed to be highly unrelated would require a paradigm shift from the past notion of 'big science' which describes extensive laboratory equipments, large critical mass of research staff and big funding and yet do not necessarily contain multidisciplinary staff, to one of a multidisciplinary partnership. Potential gains of partnership building such as increased access to ideas, technical expertise and resources as well as wider coverage and impact of research benefits has been documented (Lansang and Dennis, 2004). However, partnership building of individuals from differing disciplines is highly challenging. Success in partnership requires active efforts from all parties to

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understand why it is needed and what their distinct roles are in this partnership.

Oral cancer is one of the emerging health problems in developing countries. Malaysia as one of the developing countries suffers similar health problems. Although oral cancer is not one of the top ten most common cancers in Malaysia, it is prevalent especially among ethnic Indians where the incidence ranked within the top ten cancers in Malaysia (Lau and Zain, 2008). Preliminary data on a set of 156 cases showed that the majority of the Malaysian oral cancer patients (62.3%) were at stage IV of the disease at diagnosis hence making best available management impossible, leading to a 1-year survival of only 47.4% (unpublished observations from the OCRCC database).

Thus there is a need to shift the approach in oral cancer research in Malaysia in order to reduce this growing burden. To do this, a multidisciplinary partnership in conducting oral cancer research was initiated as a positive step towards the successful translation of research into evidence-based decision making in disease management that would benefit oral cancer sufferers in Malaysia. For decades, research partnership models in developing countries which is supported by funding agencies has always been semi colonial in nature where Western researchers led and manage the research from specimen collection especially biological materials up till research outputs in terms of publication with minimal input or control from representatives from the developing countries (Costella and Zumla, 2000). Therefore, this partnership that was developed in Malaysia which is made up of a few institutions namely University of Malaya (UM), Universiti Sains Malaysia (USM), Cancer Research Initiatives Foundation (CARIF) and the Oral Health Division, Ministry of Health (MOH) Malaysia offers a new model where local academicians, clinicians and scientists predominate research efforts towards the aim of building national research capacity. This partnership of conducting oral cancer research has existed for five years. The purpose of this paper is to document the processes and barriers experienced from research partnership building using oral cancer research in Malaysia as a case study.

Approaches

This is a case study of a developing country, Malaysia where a multidisciplinary group of researchers comprised of clinicians, pathologists, oncologists, epidemiologists, scientists and policy makers involved in the management of oral cancer patients recognised the shortcomings of research in the country where most of the studies were done on an ad-hoc basis by small groups of researchers without long term patient follow-up data. Therefore, in 2003, with the objective of providing a framework for oral cancer research via pooling and sharing of limited resources to avoid overlapping of research areas, a partnership arising from the concept of team science was initiated.

The data and tissue providers are from the academic institutions: namely, the University of Malaya (UM), Universiti Sains Malaysia (USM), Universiti Kebangsaan

Malaysia (UKM) and from the Ministry of Health (MOH) hospitals (Hospital Kuala Lumpur (HKL), Hospital Tuanku Ampuan Rahimah (HTAR), Hospital Ipoh (HI), Hospital Raja Perempuan Zainab II (HRPZ II), Hospital Umum Sarawak (HUS) and Hospital Queen Elizabeth (HQE)) in different states of Malaysia. The institutions conducting research are all the centres providing data and tissues, Universiti Teknologi MARA (UiTM) which is another academic institution and the Cancer Research Initiatives Foundation (CARIF). CARIF is a non-profit research organization with molecular biology research facilities and expertise. The partnership networking is illustrated in Figure 1. An attempt to formalize this partnership culminated in the setting up of an Oral Cancer Research and Coordinating Centre (OCRCC) in 2005. In 2008, after five years of partnership initiation and three years into the existence of OCRCC, it was timely for the team to reflect upon their strengths and weaknesses; and identify barriers needed to be overcome and to help steer the Centre towards a more effective partnership.

Conclusions

Current situation of oral cancer research in Malaysia

Strengths: Oral cancer is a major emerging health problem in Malaysia therefore justification to invest in studies to improve patient management is not difficult. The relevant authorities including the Ministry of Health have identified cancer including oral cancer as a priority research area under the 8th Malaysian Plan. The National Council on Higher Education also calls for the strengthening of research efforts and outputs. Support especially in terms of funding sources is paving the way to accelerate research in this area. For example, there is currently a strong drive towards international recognition through research where large grants are being awarded to institutions by the Ministry of Science, Technology and Innovation (MOSTI) Malaysia for the advancement of multidisciplinary research.

Another advantage that was identified is the existence of academic institutions involved in tertiary education in the field of health sciences with research-based organizations within these academic structure and research-based Non-Governmental Organizations (NGOs). These institutions contribute towards the existence of a wide range of expertise in various disciplines. In more recent years, specific academic and research organizations involved in oral cancer research in Malaysia have established a collaborative relationship with MOH, in particular the Oral Health Division. This relationship has enabled a greater networking among academicians, scientists and experts such as surgeons, oncologists, pathologists and public health epidemiologists who are involved in the management of oral cancer patients. This networking has enabled and facilitates the systematic collection of tissue and data from the increasing number of oral cancer cases in this country.

With the networking of experts from academic institutions, research-based organizations and clinicians involved in patient management via the MOH in place, this multidisciplinary approach provides a bridge for

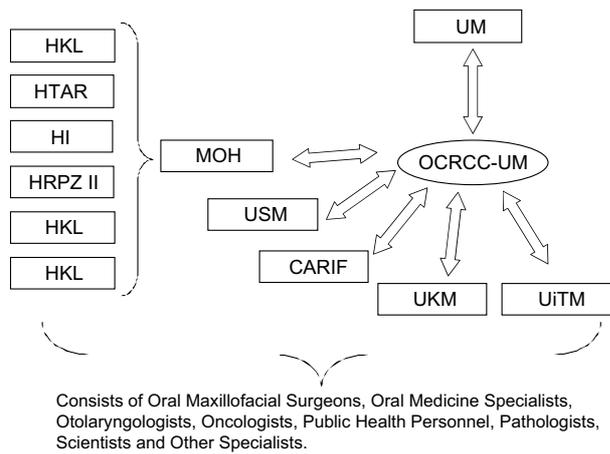


Figure 1. Institutions and Personnel Participating in the Oral Cancer Research Partnership in Malaysia

researchers to be ‘in touch’ with the target population which are the patients. Greater availability of patients, specimens and data through this networking enables for a wide range of research to be carried out by the scientists; and would in the future enable the more reliable research findings to be translated into clinical practice. The ties between academic institutions, research organizations and MOH also allows the working together of experts in their effort to search for better treatment modality and most importantly integrating research strategies with prevention programs such as screening for early detection and promotional activities. All these organizations lead to the availability of a loose research network with great national potential. Apart from the above, the international networking with other institutions formed by these institutions in Malaysia over the years serves as a platform for further research collaborations to advance knowledge through technology transfer.

Weaknesses: The main potential source of weakness identified that threatens to disintegrate this partnership is the fierce competition between the different partners in their efforts to remain viable and to justify their very own existence to the relevant funding sources. Unhealthy competition within the partnership particularly between the academic institutions where each party tries to outdo each other through international recognition via research and the desire to distinguish and propel themselves forward sometimes hinders the sharing of ideas and resources. This situation presents as a threat towards developing a workable partnership across the differing institutions as each has its own differing policies and priorities although many strive to maintain the aim of a sustainable relationship.

The research community in Malaysia is rather small and the lack of human resource remains a major issue. Currently, the main researchers from academia are full time lecturers tied down with undergraduate and postgraduate teachings and also administrative duties. Therefore, their time is divided, hence limiting overall time spent for research activities. Clinicians, who are the main source of data for cancer research are always busy with patient management, thus sometimes may overlook reporting of data for research, as their main priority is

management of patients. This lack of human capital which is imperative in carrying out the planned research activities contributed to the slower progress of research and has resulted to researchers having to find ways and means to pool limited resources together.

Furthermore, research in this area is fragmented and not holistic where there is a duplication of areas of data collection by each small individual group of researchers which is further exacerbated by the sketchy and ad-hoc publications on the status of the disease. This not only occurs in Malaysia, but also from the Asia Pacific region thus creating the dependency on literature from the Western world, which may not reflect the general Asian population. A weakness that is unique to this partnership of a multi-institution nature is that after five years of collaboration, a formal body to regulate policies regarding usage of shared data and specimens, planning of research areas and arbitrating misunderstandings have not yet been formed. The current situation justifies the setting up of the Oral Cancer Research & Coordinating Centre (OCRCC) to capitalize on the nation’s strength and to address the areas of weakness. The collaborative efforts of a partnership would enable meaningful research to be conducted for a better understanding of oral cancers and to produce results that would ultimately benefit oral cancer sufferers in Malaysia.

Stages in partnership building

Developing linkages, partnerships or collaborations is one of the six principles of research capacity building (Cooke, 2005). It was postulated that innovation, development and exchange of knowledge and skills, flexibility to respond to changes and efficiency of operation is enhanced through a partnership of a non-hierarchical organization with informal internal relationship based on trust and cooperation (Griffiths, 2000). David Wilcox (1994) in his guidebook entitled ‘The Guide to Effective Participation’ outlined the different stages in building partnerships. These stages are: Initiation; Starting; Doing; Finishing or Sustaining. Wilcox’s model in building partnerships was applied in this case study, to improve the overall oral cancer management in Malaysia.

The Initiation Stage: The impetus that spark off this initiative was the realization that the management strategy on oral cancer is still dependent on findings from the developed Western countries and that oral cancer is still detected at late stages leading to 5-year survival rates of <50% (Stewart and Kleihues, 2003). The idea of a partnership originated from a group of interested researchers from different institutions who are concerned with the direction of oral cancer research in Malaysia and realized the need for a partnership to strengthen the national capacity for oral cancer research in the country. This need arises from the fact that many studies on oral cancer in Malaysia are conducted using small samples with insufficient follow-up data, and thus can only be considered as pilot studies which do not directly address national needs. Strengthening national capacity will add to the knowledge base and improve the oral health of the community.

The Starting Stage: The next stage is the starting phase where different organizations that were either conducting research in oral cancer or were involved in the management of these patients were approached and a shared mission was developed. The initial set-up consisted of the UM, USM, the Oral Health Division, MOH and CARIF. UKM joined the partnership at a later stage while Universiti Teknologi Mara (UiTM) is the latest member to align itself with this group. The shared vision of the team is to provide a framework for oral cancer research in Malaysia via collecting and sharing of data and tissues to enable a successful translation of basic research into policy decisions making in patient care.

A mission was set to enhance relevant on-going local and regional efforts on research strategies and/or develop new strategies on:

- predicting and preventing oral cancer
- improving quality of life of oral cancer patients
- intervention of potentially malignant lesions
- management of oral cancer

These research areas coincide with the three operational interlinked categories of biomedical, health services and behavioural research described as the health research triangle (World Health Organization, 2001).

The Doing Stage: The doing stage started with obtaining funds to support the team's demand driven and locally relevant research interest. The group was able to obtain initial funding from the Ministry of Science, Technology and Innovation (MOSTI), Malaysia in 2003 to initiate projects. With this funding, networks were formed and the team identified nine hospital-based centres where oral cancer management is routine.

Activities of this phase include acquiring of equipments, hiring of human resources at each of the centre and conducting training and motivational workshops. Training was conducted by the group leader at each of the participating centres so that all personnel involved in these centres understands and are committed in working together to make this partnership a success. Benefits to clinicians and hospital staff as healthcare personnel were identified and stressed such that there is an understanding of the important role they play. The training was successful in getting the involvement of many health personnel mainly practitioners, surgeons, oncologists, pathologists and their support staff to work together with the scientists and academicians with a concept of sharing and collaborating with different institutions.

Since receiving the grant in February 2003, the doing phase has progressed to a stage where a data and tissue bank system i.e. the Malaysian Oral Cancer Database and Tissue Bank System (MOCDTBS) was developed to store the massive information and specimen collected over time. This system involves the identification of patients, collection of information and specimens at each centre and transporting/storing them at the coordinating centre for data analysis and future research. The system demands the commitment of surgeons with the assistance of research coordinators at each participating centre to ensure proper management of the oral cancer patients. These

research coordinators under the supervision of the surgeons are solely responsible for the activities at the respective centres. The availability of the MOCDTBS provided access to information and specimens among the collaborating partners.

The Sustaining Stage: The next stage is: "How do we view this partnership?" Is it a one-off endeavour or the beginning of something which ought to be sustained? The monitoring of this partnership and the evaluations of its outcome should be a regular feature with members of the core group representing the different stakeholders (UM, USM, MOH, CARIF, UKM and UiTM). Commitment from the group arose from ownership of ideas. Thus, according to Wilcox (1994), brainstorming workshops should be incorporated as regular features of this partnership where such sessions help members in the partnership to think through the practicality of ideas, and negotiating with others a result which is acceptable to as many people as possible. In this case study, projects directly related to the MOCDTBS and satellite projects were developed and eventually became the basis of postgraduate training. With increasing maturity of the MOCDTBS, more satellite projects are currently being developed with an increase in the number of participants.

The scope of research in this project has expanded and currently includes:

- simple audits of clinicopathologic parameters to determine treatment outcomes, quality of life, risk factors including studies on genetic polymorphisms (Hamid, 2008)
- genomics and proteomics
- risk predictions via conventional statistical methods and artificial intelligence

The MOCDTBS has also been instrumental in the development of the Malaysian oral cancer cell lines and cell bank at CARIF (Hamid, 2007). The dependency of these projects on this system requires the partnership to be sustained. In order to do this, there is now a need to have a sustainable human resource group with a governing body where constitutions are developed, followed and monitored by the governing body (Wilcox, 1994). Such a governing body would be responsible in developing policies on usage of data and tissue.

The setting up of the Oral Cancer Research and Coordinating Centre (OCRCC) by University of Malaya in August 2005 is a step towards sustaining these collaborative activities. The centre is being equipped with a basic skeleton human resource and a small operational budget. This partnership is now at a stage of developing its governing body called the Central Advisory Committee (CAC) which would consist of representatives of all of the stakeholders and independent scientific experts. The CAC will have to ensure that the group's aims and objectives are clear and agreed upon by members; there should be formal Standard Operating Procedures (SOPs) for decision making and solving disputes; there is a formal body to vet project applications for data and specimen usage by members; there are responsibilities and accountabilities by partners; there is accountability to funders. Thus, the CAC would continue to promote the

process of building partnership within a framework of mutual trust, shared decision-making and consensus-building which would reassure a win-win outcome for all partners. Future plans in the partnership include establishing international networking and collaboration as part of the ongoing global effort to create a healthier world and to achieve equity in global health. Building partnerships globally, however, is a big leap compared to local linkages.

Stumbling blocks in this partnership

Difficulties in maintaining a sustainable partnership has been documented. It is associated with the costs of maintaining such partnership which includes the loss of autonomy of the individual partners, the time and effort needed to build and maintain trust as well as create feelings of ownership and the diligent practice of transparency and shared decision making (Lansang and Dennis, 2004; Costella and Zumla, 2000). As in other non-formal partnerships of a smaller scale, this group faced some stumbling blocks in its effort to maintain a successful partnership. In the five years that the partnership has been in place, the biggest problem lies in the fact that there is no governing body to decide on research projects to be taken on and the vetting and usage of data and specimens.

All this while, all the projects undertaken were on an ad-hoc basis by the respective researchers without the vetting of the projects by other partners. This practice is not in accordance to the main principle put forth by Costello and Zumla (2000) for a truly cooperative and sustainable partnership which is mutual trust and shared decision making. Furthermore, the existence of three different tissue banks, managed by three different institutions makes centralized specimen tracking difficult without an on-line tracking system. In order to respect and protect all stakeholders and to maintain the trust among the partners it was realised that regular communication and information sharing is critical for the maintenance of this partnership as put forward by Baker et al (1999).

In view of this and to improve the standard of our research, the pressing need to accelerate the setting up of the CAC was addressed to ensure that research projects are known to all stakeholders and are evaluated by independent researchers not necessarily from within the oral cancer research community. This step should lead to a structured procedure of approving of projects to eliminate overlaps in research, and to avoid mistrust among the partners regarding the usage of data and specimens as all the research projects will be transparent to all parties involved. Another aspect to look out for is the multidisciplinary approach that has been taken to build this partnership. This group is a multi-institution, multi-disciplinary team made up of surgeons, oncologists, pathologists, public health epidemiologists and scientists from all over the country. A collaboration of this nature may create friction and tension among the partners as different disciplines from different institutions may have different approaches and practices on specific topics that might not be shared or appreciated by the other partners (Baker et al., 1999). Also, each partner has a different

agenda for agreeing to be a part of this large cohort, for example an academic institution might be driven by the enhancement of their teaching, grant opportunities and publications while a healthcare provider might be in it in a concerted effort to search for more effective patient management strategies. Thus, the setting up of the CAC provides a platform for all of the members to discuss and negotiate their interests in the partnership. There is an impending need to thread carefully in a multidiscipline research team as the various experts working for a common goal must not feel threatened by this diversity and inequality and they must not be made to feel that their contribution are insignificant as this will upset the harmony of the partnership. Again, the CAC serves as the governing body to resolve any disputes that might arise from these differences of opinions or practices.

Partnership maturation and transition period.

Research partnerships mature and may change over time with the different research questions asked (Baker, 1999). Apart from that, members of the partnership and the staffing of each organization may also change over the time where senior members may leave and new fresh individuals may be brought in to continue the legacy of the partnership. The inclusion of these new members may bring new perspective to the research approach that may lead to a change in the priority and aims of the partnership. Therefore, this may lead to a question of the appropriateness of sustaining the partnership. This is the stage that the team is currently at. The answer to this question requires an in-depth review of this five years partnership. For the central organization to become a formal structure representing all its initial and new partners would require gaining additional resources to meet the needs it has previously identified. But, perhaps more importantly, the development of standard operating procedures (SOPs) and guidelines of usage of resources need to be put in place such that the position of the original partners who had put in efforts and finances to build this partnership are not compromised while attending to the needs of the new partners. Then comes the question of whether the partnership should be more focussed on a particular area or need and requires the governance by two or more organization? If two or more organizations are the choice, it would be such that one would focus on grassroots involvement and responsiveness to the community while the other a more formally structured organization that would address the needs that have been defined to date (Baker, 1999), with similar considerations given to its original partners.

Summary and Conclusions

In summary, this model of partnership building in oral cancer research in Malaysia follows a ladder of participation framework where there are five levels of increasing degrees of control to the participants involved. These are: information; consultation; deciding together; acting together; supporting independent resource holder initiatives. The final controlling factor would be building a sustainable, stable relationship and strengthening trusts among the partners. The partnership in this case study

has the potential to break new grounds in ensuring that oral cancer research addresses national needs and in enhancing and sustaining national capacity for the design, implementation and management of essential research.

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