Cooperation Partners in Information Sharing within the Context of an Asian Cancer Network

Norie Kawahara

Abstract

It would be a great mistake to analyze the health situation in Asia relying on the focus on individualism inherent in the sense of values of Europeans and Americans. Cooperation across fields is indispensable for effective control of the epidemic of disease we are facing in the 21st century. We need to concentrate efforts on bringing together specialists, not only within the various areas of medical practice, but also across such fields as economics, politics and information technology (IT). Asia differs from Europe and America in that it does not have any group political structure and therefore we must rely on voluntary integration of our efforts if we are to achieve the most effective application of our combined resources. Non-intervention in internal affairs is naturally a very important condition for success. Sharing of information while abiding by national regulations regarding medical data confidentiality does pose difficulties, but gentle persuasion to standardize processes with a shared commitment to overcoming problems should reduce opposition. Our common purpose in maintaining healthy societies, whether we be scientists, medical staff, economists, computer specialists or politicians, provides the bond. Ways and means by which this bond can be strengthened deserve our attention.

Key Words: Development economics - nonintervention in internal affairs - IT - solidarity

Cancer and Other Non-Communicable Diseases are Increasing Rapidly in Asia

Average life expectancy in Asia is increasing with improvement in the standard of living accompanying economic development, but one downside is that the problem of cancer and other chronic diseases is thereby assuming greater importance. With the lack of necessary medical infrastructure in many of the developing countries, we need to build action plans for cancer control taking into account limited medical resources (finance) and competition from infectious diseases which occupy a larger place in the consciousness of many decision-makers. Greater appreciation of the importance of non-communicable diseases in developing countries is a high priority. Building an effective means to share cancer and related information in Asia is therefore an urgent business. In the present commentary, development of a network of interested parties is advocated with active involvement of government policy-makers, academia, the IT industry and relevant NGOs.

Several questions arise because of the special features of Asia, with its wide variation in levels of economic development, inequalities in income distribution, different religious persuasions and social structures. It is essential to identify the major role players and couch appeals for their cooperation in language that they can readily understand.

Necessity for Collaboration with Economics Specialists

Cancer and other chronic diseases clearly differ from acute infectious disease in terms of the temporal perspective. The underlying risk factors are long term and it is necessary to consider the economic implications from this perspective. An appropriate analysis of social space in Asia is necessary, with due consideration of developmental policies and strategies within developmental economics, to provide a firm framework. Problem solving-like-oriented policy-like learning will gain from quantitative measurement and qualitative consideration of financial development for setting agendas. It can be said that a common language has already been formed between economics and epidemiology with the United Nations Development Programme (UNDP) introduce the concept of living quality and measures based on the human development index (HDI). It is also apparent above all that establishing good matches between researchers in such different fields will provide a strong argument for cooperation.

How to Avoid Disturbing Cultural Sensitivities in Internal Affairs?

Lifestyles, financial levels and characteristics of societies differ very greatly across Asia. In particular, the
impact of the religious environment is major. Nevertheless cultural exchange is very popular and finds support so long as national sensitivities are taken into account. Voluntary integration through feelings of sharing and solidarity might be an effective standard, in place of the European Union or structural agreements like the North American NAFTA.

Therefore we should place emphasis on our very profitable duty to cooperate within and between countries in our collection of information for effective disease control.

Standardization of Information Collection and Use of IT

As I earlier stressed in this journal, participation in an international common clinical trials is essential for new therapeutic regimens specifically for Asian consumption (Kawahara, 2007). Innovative drug development should have a close connection with epidemiology information utilizing all the advantages accruing from application of IT software and the world wide web. Advances in medical treatment for cancers are hardly conceivable without fusion of information technology and post-genome science in real time. Clinical data from a patients case records in hospital can thus be readily transmitted along electronic pathways and gathered together with genomic data to form a Medical Information Repository (MIR) following global standards.

How to Live with Personal Information Protection Regulations?

Much of the content of international standards at present is based upon Organization for Economic Cooperation and Development recommendations about personal information protection. However, there are those who argue that the driving force is European and American financial capital accumulating personal information to facilitate expansion of markets. Clearly, misuse of data to the detriment of the lives of individuals in whatever form needs to be strenuously avoided. This is a very difficult problem for consensus building because it involves multiple interests. With genetic information in particular, large restrictions have also begun to be placed on international access, conforming to a security par and a regulation of ethics. Anonymity needs to be guaranteed by whatever approach appears most appropriate (Hamajima et al., 2004). The most important point to stress is that policies concerning the disclosure of electronic health records can be reliably and efficiently enforced and audited at the database level without revealing individual patient identities or compromising security or privacy (Agrawal and Johnson, 2007).

Gentle Persuasion for Solidarity

Arguments for databasing of Asian purposes should be advanced urgently, first using cancer registration as a concrete example. Accumulation of the data for other diseases and for clinical studies will then follow on naturally. Of prime importance is convincing the politicians of the necessity for safe data collection. Whether this is at the national or local level (Moore and Tajima, 2006), all of the major players need to interact in a culturally sensitive way to achieve effective data collection for chronic disease control.

References


