

**KEYNOTE ADDRESS BY DIRECTOR-GENERAL OF HEALTH DATUK DR
HASAN ABDUL RAHMAN AT THE OPENING OF THE NATIONAL
CONFERENCE FOR CLINICAL RESEARCH 2011 (NCCR 2011) & LAUNCH
OF CLINICAL RESEARCH MALAYSIA (CRM) ON 22 JUNE 2011
(WEDNESDAY) 9.00 AM AT THE SUNWAY PYRAMID CONVENTION
CENTRE, PETALING JAYA, SELANGOR**

TRIALS, REGISTRIES AND DATABASES: MANY ANGLES, ONE AIM

Salutations

Assalamualaikum wr wb. Good morning and Salam1 Malaysia. Welcome to Malaysia for our foreign speakers and participants.

It is an honour to be speaking to you today on a topic, “Trials, Registries and Databases: Many Angles, One Aim”, that is the cornerstone of healthcare excellence in Malaysia, especially in view of the Economic Transformation Programme (ETP). A national healthcare system, just as in clinical research, requires accurate and credible data as the critical component in decision making, in order to continuously improve quality while maintaining cost effectiveness in the delivery of health care.

Indeed, Malaysia’s framework to strengthen the health system is based on a multi-disciplinary care team approach, well-trained human resource, evidence-based decision support tools and effective clinical information systems. Patient registry has four main objectives, it aims to study the natural history of disease, to determine clinical and cost effectiveness of treatment, to monitor safety and harm of therapeutic agents and to evaluate access to and quality of healthcare for target disease.

With this in mind, the Ministry, through efforts of the Clinical Research Centre, are currently sponsoring over 30 patient registries, and the National Healthcare Statistics Initiative. Of the 30 patient registries, the oldest is the National Renal Registry (NRR). As of March 2011, the NRR has cumulative 660 source data providers (SDP) and 51,516

total data submission for dialysis and transplant. The National Eye Database, established in 2002, has 36 SDPs with 98,230 data submissions for cataract surgery and 43,821 for diabetic eye surgery. This gives you an idea of the huge amount of data that can be accumulated and analysed.

These databases and registries, compiled from existing records and from specifically designed surveys, are powerful tools to be used in patient recruitment for clinical trials and in evidence-based policy-making. Patient registries collect information on patient treatment outcome at individual level whereas healthcare statistics are center-level resource data. A combination of both of these data will give a clearer idea on healthcare performance.

Thus, the National Healthcare Statistics Initiative (NHSI) was initiated in 2009 to collect data on the services, facilities, workforce and medical technologies available in the country to better understand the healthcare system. I am happy to inform that the NHSI has recently published the National Healthcare Establishments & Workforce Statistics (Primary Care) 2008-2009, the National Healthcare Establishments & Workforce Statistics (Hospitals) 2008-2009 and the National Medical Device Statistics 2009. We hope that these NHSI reports will lead to better policies and healthcare outcomes.

Future plans include a situational analysis with Malaysian Administrative Modernisation and Management Planning Unit (MAMPU) for solutions based on long term sustainability of these patient registries. These registries and databases have benefitted from advancements in Information and Communication Technology and the increasingly paperless nature of maintaining patient records. With ICT, the collection, use and storage of medical information have made it easier to access for use and reference, in strict compliance with privacy and confidentiality guidelines.

In Malaysia, under the National Key Economic Areas and the recently announced National Digital Masterplan, the state-of-art ICT infrastructure will be faster and more reliable with availability of broadband access nationwide. This upgrading of bandwidth will have positive impact on Ministry initiatives such as eHealth, telemedicine, clinical research and the Diagnostic Service Nexus project aimed at improving radiology services.

This will also benefit the proposed National Health Data Warehouse under the National Informatics Centre and the implementation of Hospital Information System (HIS) for all MOH Hospitals. Managing data collected through these various efforts will require knowledge and expertise on how institutions can use such data to benchmark against international standards and identify areas for improvement. Adopting a more forward-thinking strategy in data analysis will mean asking specific questions for clinical researchers to develop new interventions which will then be subjected to rigorous clinical trials.

It is interesting to note that ClinicalTrials.gov, a United States government sponsored registry of nearly 100,000 clinical trials around the world, is now planning to build a registry of patient registries. This is aimed at creating a 'metaregistry' that will enable doctors, patients and researchers to contact a given registry owner to obtain data of individuals willing to take part in observational medical studies.

This “boundaryless” aspect of ICT will require extra vigilance in the protection of patient’s records against abuse. With the implementation of ehealth, Malaysia is also looking into data privacy protection laws. Findings of a global survey unveiled at the World Health Congress in April this year showed that Telehealth and related technologies has enabled collaboration and information-sharing among healthcare professionals. Among others, the survey identified top three technology that can transform healthcare as; collaborating via ICT to diagnose and treat patients; electronically sharing or accessing diagnostic images, video, or patient biometric data; and providing clinical training and references via ICT.

A recent Ministerial eHealth Conference in Budapest, Hungary has called for more compelling evidence on the benefits of telehealth applications and for a better engagement of patients and healthcare providers. Also of interest will be the findings of the clinical trial for telemedicine currently under way in nine European regions with 7,000 patients: the Renewing Health project, to assess the impact of telemedicine on healthcare. I understand that countries like Australia, through the National Health Information Management Advisory Council’s Health Online: A Health Information Action Plan for Australia¹, provides strategy for information management and the use of online technology within the health sector.

I am sure we will be able to learn more from our distinguished speakers over these next few days. I wish you a pleasant stay and a fruitful conference.