

Technical services available CRC to support the establishment and operations of clinical databases and registries

1. Clinical Epidemiology Expertise

Expertise in clinical epidemiology is obviously required in the **design stage of a registry** when methodological issues are being worked out. Questions such as registry purposes (often couched in epidemiological terms), case definition and scope, data collection instrument, reliability and validity of measures, etc need to be asked at the design stage.

Clinical epidemiology input is also required at the stage of **data analysis, and interpreting the statistics** generated from the registry's database. While interpretation of much the results (disease or treatment incidence and prevalence, mortality rate & risk, survival probability, odds & hazard ratio, etc) may be familiar to most doctors, the results may however be distorted by the methodology and registry operations, such as potential for bias, confounding, measurement error and case ascertainment, etc. One will need the skillful eyes of a clinical epidemiologist to descry this, and make amend or caution accordingly.

CRC has such expertise from its Clinical Epidemiology Unit. A clinical group contemplating establishing its own database may avail itself to the service of the Unit.

2. Biostatistical Expertise

This is also required both in **registry design stage** (issues of sampling, sample size planning etc) and more obviously, at the **data analysis stage**. It always surprises us that there are registries in this country that operates without the service of statistician.

CRC has contracted such services from a vendor company (Biostat Consult) for our own research needs. A clinical group contemplating establishing its own database may avail itself to the service of our consultant biostatisticians.

3. Information and Communication Technology (ICT)

This is another one of those things one could not do without in operating a modern registry.

CRC offers the following services:

1. IT system to support registry administration, site management (a site submit data to the registry), and for data capture whether by paper form or through the web
2. Hosting the database on the registry behalf in a highly secured data centre (we have a contract with NTT in Cyberjaya for this). This is critical because unlike clinical research, registry always collects identifiable data with patient's name and IC. So we don't put the data in CRC's server, which is NOT secured enough for registry data even though we probably have the most secured system in the MOH
3. Registry website maintenance. All registries should have one to communicate with sites and stakeholders, and to enable data & report download by sites and users
4. Highly specialized data processing services such as data auto-coding, records de-duplication (often a subject may be notified more than once to the registry, for eg average cancer notification to cancer registry is 1.9), records linkage (registry may need to access information in other databases, such as another registry database, HMIS hospital discharge database, death register from Jabatan Pendaftaran Negara). Such data processing utilizes state of the art technology, which are very expensive.