

MISSION REPORT ON CANCER REGISTRATION IN THE PHILIPPINES

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A mission to the Philippines was conducted by Dr Parkin on 14 - 15 September 2011 to assess cancer information and visit cancer registries. This visit completed the comprehensive needs assessment of the country's cancer control capacity carried out during the imPACT mission to the Philippines on 28 - 30 March 2011. Dr Parkin was nominated by IARC to take part in the mission but was unable to participate at the time.

See Annex 1 and 2 for mission agenda and list of people met.

1. CURRENT STATUS OF CANCER REGISTRATION

At present, there are three population-based cancer registries operating in Philippines, two in the greater Manila area, and one serving Metro-Cebu. Due to time constraints only the two Manila registries were visited. Therefore, the bulk of this report concerns their operations and recommendations for improvement.

Philippine Cancer Society-Manila Cancer Registry (PCS-MCR)

The registry covers the four major cities (Manila, Quezon, Pasay, Caloocan) of the National Capital Region (NCR), the major urban centre of the country. The registry was established in 1983, based on the former "Central Tumor Registry of the Philippines" (CTRP) created in 1968, which had covered 25 hospitals in Manila and one in Cebu (relying on passive notifications). Cancer registry clerks actively collect pertinent information from medical records, radiotherapy records, pathology/haematology records and hospital tumour registries, abstracting relevant records onto registry notification forms. Death certificates from the office of the Local Civil Registries are also reviewed; those mentioning cancer are transcribed onto a copy of the registration form. The registry staff also visits selected private surgeons, oncologists and haematologists. The registry is located in the Philippine Cancer Society (PCS) building, and is fully funded by the PCS. The registry staff comprises one full-time supervisor, and six cancer registry research assistants.

Data received are checked manually and electronically for completeness and consistency as well as for duplication. Coding consistency and validity is checked with the IARC/IACR CanReg-4 software. Follow-up is done by the matching of death certificates. In 1997, however, PCS-MCR conducted its first population-based survival study on the 1987 incident cancer cases, using both active and passive follow-up (published in Sankaranarayanan et al, 1998). A subsequent study followed up a random sample of incident cancers of breast (500), cervix (500), colon and rectum (300) registered in 1994-1995. The results were published by IARC in 2011 (Sankaranarayanan et al 2011).

The Department of Health – Rizal Cancer Registry (DOH-RCR)

This was the first population-based cancer registry in the Philippines, established in 1974 as one of the activities of the Community Cancer Control Programme of the province of Rizal. It covers the 26 municipalities of the original province of Rizal. Twelve of these municipalities

were incorporated with Metro Manila in 1975; only three municipalities can be considered “rural”. The DOH-RCR is located in the Rizal Medical Centre in Pasig City. It was initially funded by the Rizal provincial government but since 1975, funding has been a full responsibility of the Rizal Medical Centre. Its present staff consists of a medical oncologist who heads the registry, and two full-time registry clerks.

Data collection has been active since 1980 (involving case finding and abstraction by registry staff). Hospital data sources include medical records, pathology and haematology records and logs, radiotherapy records and the hospital tumour registry (if available). Private clinics of oncologists and hematologists are also covered. Death certificates mentioning cancer are also abstracted in the local civil registry offices in the municipalities and cities of Metropolitan Manila and Rizal province. Data are checked for completeness and accuracy, matched with the master patient index file of the registry to check for duplicates, and managed using the IARC/IACR CanReg software.

Follow-up is mainly passive (via the death certificates), but the registry also participated in the active follow up of 1987 cases (in 1993) through the attending physicians, health centres, as well as letters and home visits (published in Sankaranarayanan et al, 1998). A further study estimated cancer survival from 1570 cases of cancer of the breast registered in 1996–1997, and was reported by IARC (Sankaranarayanan et al 2011).

The results from these two registries have been published in the “Cancer Incidence in Five Continents” series of IARC, which is taken to be a mark of quality, in that only datasets deemed to be suitable for international comparisons can be included.

The schedule of appearance in these volumes is as follows:

<i>Volume</i>	<i>V</i>	<i>VI</i>	<i>VII</i>	<i>VIII</i>	<i>IX</i>
Philippines, Manila		1983-87	1988-92	1993-97	1998-2002
Philippines, Rizal	1978-82	1983-87		1993-97	

The main problem of the two registries (and one that has impeded publication of the Rizal data) is that a relatively high percentage of registrations are from a “Death Certificate Only” (DCO). These are cases where an individual has died, and cancer has been entered on the death certificate. The registry is notified of the case, via the death certificate, but no trace of the case can be found in any hospital record (especially for those cases that died at home). A high percent of DCO cases is taken to imply inaccurate data (in that the diagnosis is uncertain), or incomplete case finding (cases are dying, but not being found by the case – finding procedures while still alive).

Both registries have made efforts to reduce the high percentage of DCO cases. The Rizal registry has attempted a more thorough trace-back of death certificate notifications in hospitals and at place of residence, particularly for liver cancer cases. The Manila registry undertook a special study on 1993–1997 registrations. Home deaths were investigated by contacting relatives. This showed a substantial level of error in certification – with liver cancer, especially, being over-recorded as a cause of death (Turano et al, 2002).

The results of these two registries also provide the most important component of the regular publications “Cancer in the Philippines” (four volumes, the most recent in 2011) and

“Philippine Cancer Facts and Estimates”. These provide a very valuable resource to the cancer control programme, with information on geographic patterns and trends within the greater Manila area, and estimates on the national cancer profile. Both registries collect extensive information on “Extent of Disease” and the Rizal registry collects, in addition, AJCC Stage and TNM on all registered cases (although these latter are not currently entered into the registry database). However, these data are not reported in the PCS publications. Neither is survival, although, as described above, survival data (stage specific) have been reported in IARC publications. It is not, therefore, necessary to estimate “curability” from the ratio of recorded deaths and cases, and it would be misleading to do so, not least because of the known inaccuracy of death certificates, as earlier described.

2. PROBLEMS IN CANCER REGISTRATION

Despite their long history, and valuable database on cancer going back more than 30 years (a very rare resource in low- and middle- income countries) the registries experience several problems.

1. Funding. Core funding comes from Rizal Medical Center and PCS. Given the laborious manual methods used by the two registries, these funds do not provide for sufficient staff for data capture and recording. Funding has been supplemented from time to time by grants from IARC (especially in relation to the breast cancer screening studies), and special funds from DoH. The most recent funding from the latter source terminated at the end of 2011. Both registries have ceased data collection, and are currently engaged in verifying and entering data on cases diagnosed in 2003–2007 (working especially on data from 2006 and 2007). This is because of the perceived importance of being able to submit their data for the next edition of “Cancer Incidence in five Continents” (CI5), the call for which, involving data for this period (2003–7) has just been launched.
2. Slowness of operation. Related to the registries fixation on publication in “CI5” data collection is proceeding in five-year cycles. No data have been collected since 2007, so that, even if full staffing were achieved, hospital visits would entail tracing cancer patients (and their records) from the last 4 years. It means that the process is very slow, and up-to-date data for the whole registry area can never be produced (the most recent data in “Cancer in the Philippines” dates from 2002).
3. Manual methods. The registries have developed a methodology that has changed little in the last 30 years. It depends on case finding by registry clerks, and abstraction onto paper forms. It seems highly likely that some of the data sources they are using are now computerised (the big new private hospitals and laboratories, for example, and, most likely, death registrations). Currently, there seems to be no use made of such computer datasets. The option of direct data entry into CANREG (onto personal computers or PDAs), seems not to have been explored, although it could speed up data verification, and reduce form-filling.
4. Poor quality death certificate information. This is out with the registries immediate control. However, it is a major problem, not only for the validity of the registry data, but in hampering national disease surveillance in general.

3. RECOMMENDATIONS

1. The status of the Cebu registry should be ascertained, much in the same way as those of the Manila area.
2. These registries are a very valuable resource. Indeed, given the deficiencies of mortality data. They provide the backbone of cancer information for disease surveillance and monitoring as part of the national cancer control programme. It is recommended that they receive regular funding from DoH to allow them to fulfil this role.

In the short term, funding is needed not only for staff to ensure routine functioning, but also to eliminate the backlog of cases (from 2007 to current). The registries should aim to complete data collection for 2007–2013 by the end of 2014, and should estimate their requirements to do so (in terms of staff, equipment, and operating expenses). Thereafter, data collection should proceed in annual cycles, with a report for 2014 being available at the end of 2015.

Appropriate staffing for this latter function (annual data collection) needs to be identified, with the aid of an expert on cancer registration methodology. They would also review current methods.

Switching to passive notification of cancer cases (by medical staff), as has been suggested, is not advisable. The Rizal registry itself notes that “Although cancer is reportable by legislation, passive data collection proved unsatisfactory”, and this has been the experience in population-based registries elsewhere. While “compulsory notification” is valuable in precluding objections to access to data (on confidentiality grounds) it will not ensure compliance. What is more, it seems evident that highly trained medical staff are not best employed in routine clerical tasks that are better undertaken by dedicated staff trained for the purpose.

3. In the interim, it is suggested that the publication “Cancer in the Philippines, Vol IV Part 2 (Incidence Rends 1980-2002) be updated to 1980-2007, when data entry and checking for the final five year period is complete. Then, using this material, some short – term projections (to 2012) could be produced. The methodology is not difficult, and the results not likely to be far from reality, when the projection period is short. The statisticians that produced the original report might be asked about their availability for this task.
4. A review of registry methods is important, with a view to automating as much of the data collection as is feasible, given the current status of hospital information systems in Manila. In this context, the availability of computerised death registrations should be investigated (see 7 below). The feasibility of using PCs or PDAs at the time of data abstraction should be explored.
5. The registries are currently using CANREG-4, which is performing well. However, when the data analysis options of CANREG-5 have been expanded, they should consider changing. The major advantage would be to permit networking of the CANREG database, and remote data entry.
6. DoH is introducing an “Integrated Chronic NCD Registry System” (INCDDS). One (of five) components is cancer. Notification of cancer cases will take place from

hospitals, using electronic patient record systems (if available) or data entry by medical record officers (MROs) when not.

It is not clear at present how expensive or successful this system will be (implementation begins later this year). However, although very likely to be incomplete, reports of cancer in residents of the population-based registry areas would provide a valuable extra source of information to the registries. What is more, the registries will provide an independent evaluation of completeness of the INCDDS, at least for cancer. In this context, it is very important that the two data sets (INCDDS and cancer registry) are coherent, and it is to be regretted that the registry directors were not consulted during its formulation.

Attempting to collect risk factor information (diet, alcohol, HPV status) in the same way as demographic and disease-related information, as proposed in INCDDS, is inappropriate, and at best likely to be very incomplete and biased. It will place an unnecessary strain on what will already be a very difficult data collection exercise.

7. National mortality statistics are prepared by the National Statistics Office. Although not routinely available internationally (the most recent available on WHO website are from 1997), and evaluated of only "medium" quality (see Mathers et al, 2005), the ability to produce such data implies that the death certificate data are being computerised. Access to a computer file of deaths in residents of the registry areas would be highly valuable. It would reduce the need for manual capture of cancer – related deaths, and allow updating of vital status (and expeditious production of survival statistics).

The availability of such data needs to be explored, if necessary at a high inter-departmental level.

In addition, it would be highly desirable to set up studies on the quality of information on death certificates (at the least, in the Manila area), and to investigate methods of improvement. The possibility could be explored with the Public Health Faculty of UP. As noted earlier, improving the poor availability and modest quality of mortality data should be the highest priority in disease surveillance in general (and cancer control in particular).

8. The possibility of setting up a cancer registry in Mindanao was explored in 1998. Davao City was selected (as the major referral centre) and some resources were provided via the A Soriano Foundation. To better estimate the cancer profile in the whole country, it would be highly desirable to establish a registry there (in addition to Manila and Cebu). A consultant visit is required to report on feasibility and likely costs.

References

Mathers CD, Fat DM, Inoue M, Rao C, Lopez AD. Counting the dead and what they died from: an assessment of the global status of cause of death data. *Bull World Health Organ.* 2005; 83:171-7.

Sankaranarayanan, R., Black, R.J. & Parkin, D.M. (Eds) (1998) *Cancer Survival in Developing Countries*, IARC Scientific Publication No 145, International Agency for Research on Cancer, Lyon, France.

Sankaranarayanan R, Swaminathan R, Lucas E (eds) (2011) *Cancer Survival in Africa, Asia, the Caribbean and Central America*. International Agency for Research on Cancer, Lyon, France.

Turano L, Laudico A, Esteban D, Pisani P, Parkin D. Reduction of Death Certificate Only (DCO) Registrations by Active Follow Back. *Asian Pac J Cancer Prev.* 2002; 3(2):133-135.

ANNEX 1–PROGRAMME OF THE MISSION

Sept 14, 2011

- 8:00 AM-10:00 PM – WHO Conference Room, Building 3, DOH, Sta. Cruz, Manila
- 11:00 AM-1:30 PM – Rizal Medical Center, Pasig City
- 2:30 PM-4:30 PM – Philippine Cancer Society, Inc, San Miguel Manila

Sept. 15, 2011

- 1:00-5:00 PM - National Epidemiology Center, Conference Room, 2nd Floor, DOH, Sta. Cruz, Manila

Agenda:

1. Overview and Objectives of Visit of Dr. Parkin
2. Presentation on Cancer Registry
 - Integrated NCD Registry-Ms. Cherry Esteban-IMS DOH
 - Overview of Population Based Cancer Registry & Result of 2010 Facts and Estimates- Phil. Cancer Society
3. Debriefing with NCDPC Officials and Stakeholders

ANNEX 2–LIST OF PERSONS MET

Department of Health

Dr. Liliberth David	Director, NCD
Dr. Agnette Peralta	Director, Bureau of Health Devices & Technology
Dr. Ma. Elizabeth Caluag	DDO-NCDPC
Dr. Ernie Vera	DDO-NCDPC
Dr. Franklin Diza	DDO-NCDPC
Dr. Ma. Cristina Galang	DDO-NCDPC
Ms. Remedios Niola	DDO-NCDPC
Mr. Giovanni I. Infante	DDO-NCDPC
Dr. Agnes Segarra	NEC
Dr. Ma. Corazon Teoxon	NCHFD
Dr. Allan Evangelista	BIHC
Ms. Jovita Aragona	IMS
Ms. Cherry Esteban	IMS

WHO Country Office

Dr. Soe Nyunt-U, WHO Representative
Dr. John Juliard Go, Professional Officer NCD

Philippine Cancer Society (PCS)

Dr. Rachael Rosario, Administrator
Prof. Adriano Laudico, Director, PCS registry

Rizal Medical Centre

Dr. Relito Saquilayan, Hospital Director
Dr. Maria Rica Mirasol-Lumague, Director, DoH-Rizal registry