A Future

HOW TO ESTABLISH GOOD INFORMATION FLOWS

Establishing good information flows between cancer registries and the clinical community helps ensure that the registry generates useful, clinically relevant information. Cancer registries should discuss their annual reports with clinicians: these discussions will allow the registry to show clinicians that added “paperwork” actually allows for an understanding of cancer patterns that can inform strategies to reduce the cancer burden and impact at a population level.

Registries should also attempt to engage clinicians in ongoing discussions regarding disease incidence, mortality, the impact of therapy, and other health interventional resources. In settings where such communication is absent or not yet routine, organizing working groups around data collection, clinical practice, and clinical outcomes on a monthly or bi-monthly basis would be a good start. These working groups should be multidisciplinary and where this expertise is available should include:

- Population health professionals
- Registrars or data technologists
- Clinicians, particularly oncologists
- Pathologists
- Diagnostic imaging specialists
- Other healthcare professionals, and where applicable local influencers who may encourage collaboration

The goal of these working group meetings should be to develop protocols and data exchange approaches. In addition, these meetings should impress upon overworked clinicians how recording and reporting clinical data to the registry enhances the value of clinical interventions. Face-to-face meetings can be complemented by telephone and e-mail exchanges where available and may develop into regular or automated information submissions over time. Clinicians may eventually even wish to become involved in writing scientific publications based on registry data.

THE ROLE OF THE GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENTINLOW-ANDMIDDLE-INCOMECOUNTRIES(GICR)

GICR is an international effort convened and coordinated by the International Agency for Research on Cancer (World Health Organization). In collaboration with partners the world over and its network of regional hubs, GICR offers assistance to national authorities in planning and strengthening cancer registration through methodological, technical, educational support and collaborative research. This factsheet is part of the advocacy efforts of GICR.

Do not hesitate to contact GICR to discuss the improvement of cancer registration in your country, and explore ways to increase communication between your cancer registry and the clinical community.

Learn more at http://gicr.iarc.fr **Contact us at gicr@iarc.fr**

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International Agency for Research on Cancer
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Effective communication between cancer registries and clinicians:

Working together to improve patient outcomes

Accurate information about a region’s cancer burden is essential for determining healthcare priorities and targeting cancer control activities. Population-based cancer registries provide this information by collecting data about cancer cases in a certain geographical area – a task that requires the cooperation and involvement of clinicians.

DIFFERENT WORKING ENVIRONMENTS, COMMON GOALS

Cancer registrars are data management experts who compile case information in order to assess the burden and impact of cancer at a population level. Registrars may not be aware of the impact that health system capacity, resource allocation, or system performance has on patients’ clinical care. Clinicians, who take personal responsibility for the health of individuals receiving their care, may not be informed about the population burden of disease or how resources could be allocated to best serve their region’s needs.

Good information flows between registrars and clinicians can help ensure that patients’ needs are addressed on both the population and individual level.

Successful cancer registries communicate regularly with clinicians, who help ensure that the registries collect complete, high-quality data. In turn, cancer registries provide clinicians with information about cancer trends and success of treatment that informs their clinical practice.

Facts

UNIQUE CHALLENGES FOR LOW- AND MIDDLE-INCOME COUNTRIES (LMIC)

Barriers to the effective implementation and use of registries for clinical practice and disease control are not unique to LMIC. However, LMIC may face unique challenges related to limited resource availability, lack of governance or specific local situations. These challenges include the following:

☐ **LACK OF MEDICAL FACILITIES.** The small number of medical facilities for diagnosis and treatment of cancer in LMIC, particularly in rural regions, forces many patients to travel to urban medical centers, or even go abroad. This unfortunate situation affects registries in their efforts to gather data on the cancer burden in the population.

☐ **LOW CANCER AWARENESS.** Cancer awareness is generally low among LMIC populations. Many people do not seek diagnosis or treatment for their cancers – which means that those cases will not be registered and the registry's assessment of cancer burden will thus be partial. Furthermore, a large number of patients who do visit health centers do so when their cancer is advanced – and late presentation is a poor prognostic factor for survival. Community healthcare workers encouraging suspected cancer patients to seek medical care make a contribution on both the individual and the registration levels.

☐ **POOR FOLLOW UP.** Following up patients after they leave the health center is a real challenge in settings where people may not have a fixed address, or live in settlements which are not properly mapped. For the individual, this may mean not completing treatment. For registries, lack of follow up results in non confirmation of suspected cases, incomplete clinical data and absence of outcome information – information which the clinician caring for patients would want to know.

☐ **POORLY MAINTAINED RECORDS.** Medical and death records in LMIC are often poorly maintained for many reasons, including low literacy rates and a lack of centralized record systems. If records are incomplete or missing, registrars will struggle to compile accurate and complete case information.

☐ **LACK OF TRAINED STAFF.** The low availability of and access to training can be real barriers in many countries. Building capacity can, however, be a double-edged sword for cancer registries: it is not rare that newly acquired skills become interesting to better paying employers - coupling the training with the retention issue. Lack of trained staff in data abstraction, ICD coding, data analysis and data utilization results in poor quality data which cannot be utilized for public health purposes.

With so many potential hurdles, it may seem difficult or impossible for LMIC to establish accurate and timely data collection systems. But it can be – and has been – done. For example, the Barshi Rural Cancer Registry, India's first rural cancer registry, established a set of **communication-centered data collection methods** that LMIC registries should be encouraged to consider.

BRINGING TOGETHER PROFESSIONAL COMMUNITIES: THE BARSHI RURAL CANCER REGISTRY SUCCESS STORY

To accurately estimate cancer burden in India, registries must document cancer incidence and mortality in rural areas, which are home to over 70 percent of the country's population. The Indian Council of Medical Research in collaboration with the Tata Memorial Hospital established India's first rural cancer registry in the Barshi region in 1987. Today, the Barshi Rural Cancer Registry covers 346 villages and a population of 0.5 million people.

To overcome obstacles including lack of medical facilities and low cancer awareness among the Barshi population, the Barshi registry developed an innovative methodology. Communication between registrars and clinicians plays a central role. The registry deploys trained field workers to Barshi villages every six months to meet with local clinicians and collect information about proven and likely cancer cases. The workers also interact directly with the village population by holding educational meetings designed to increase cancer awareness and by conducting household visits. The workers collect information about deaths from the home visits and from local offices. In addition to the village visits, registry workers regularly travel to primary care centers, major hospitals, and nearby urban registries to gain additional information about cancer cases.

The efforts of the Barshi registry have paid off: the registry generates useful cancer incidence and mortality data while increasing cancer awareness among rural populations. For example, two studies published in 1995 and 1998 showed that increased cancer awareness among the Barshi population resulted in increased early-stage cervical cancer diagnosis and cervical cancer survival. Furthermore, the registry was useful to evaluate the cervical cancer screening programme which had been set up in the region. Linkages with the registry helped to demonstrate the usefulness of the HPV test as a screening tool for reducing mortality from cervical cancer, as documented in a peer-reviewed publication.

Figures

REGISTRY DATA INFORMS CLINICAL PRACTICE

Clinicians can help registries gather useful data by communicating with them about individual cases and keeping thorough medical records. But registries are not the only ones to benefit from this communication. **Cancer registries inform clinical knowledge and practice** in many ways:

☐ Information from cancer registries helps clinicians become familiar with patterns of cancer.

☐ Cancer registries report survival statistics, which help clinicians understand the average prognosis of cancer patients in a population. This knowledge gives clinicians an indication about the effectiveness of current cancer care.

☐ Registries can report to rural clinicians how many cancer cases they registered from urban medical centers in order to provide a more accurate picture of cancer in the rural population. Clinicians can use this information to inform healthcare policy makers about where resources should be allocated in order to ensure that their region has sufficient diagnostic and treatment facilities.

☐ Cancer registries can support clinical research activities, such as case-control and cohort studies to establish aetiology, risk or causal attribution, as well as community intervention trials and cancer screening programs monitoring to establish effectiveness, efficiency and cost-benefit.

A CANCER REGISTRY MINIMUM RECORD contains details of patient identifiers, basic demographic information and information about the cancer:

- Registration number
- Source of information
- Patient identification
- Sex
- Age
- Date of birth
- Place of usual residence
- Duration of stay in registry area
- Date of incidence
- Basis of diagnosis
- Tumour site
- Tumour morphology
- Tumour behaviour
- Tumour sequence number

Additional data, when recorded consistently, will improve the value of the output from the registry and may include (among others): population subgroup, place of birth; date of immigration; grade of tumour; method of first detection; clinical extent of the disease at diagnosis; tumour stage; site of distant metastases; initial treatment; recurrence; cause and place of death; risk factors…

It is important that the registry operate following international standards and tested categories and codes, and develop a manual with definitions of internal codes and processes. Standardisation is the first requirement of quality data, since it facilitates data processing, helps avoid errors, ensures continuity and enables comparisons.