

The Creation and Maintenance of a Hospital-Based Cancer Registry System

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Abstract

Introduction: Cancer registries contain information essential to any rational program of evidence-based cancer control, including cancer epidemiology and outcomes, and can be site-specific, hospital-based, or population-based. The creation of a national population-based cancer registry and hospital-based cancer registries was mandated in the National Cancer Control Act of 2019. This paper reports on the creation and maintenance of the Cancer CARE Registry and Research Philippines (CARE PH) app, the country's first hospital-based cancer registry system, and its future directions in registry and research.

Methods: A cancer registry in the form of a web-based application was developed through the collaboration between a clinician and a health information technology specialist. This registry was designed to follow the cancer patient's journey from diagnosis to staging to treatment and cure, relapse, or progression into death. Patient information is collected in a structured and secure process from designated catchment areas in each hospital by trained tumor registrars, with the main catchment area being the hospital's Surgical Pathology department. The CARE PH application is given to member hospitals for free through the support of grants given to the CARE PH Foundation, Inc.

Results and discussion: Today, 31 member hospitals in the CARE PH system have recorded a collective total of 9,880 new cancer patients for the year 2020. The most common cancer types recorded in CARE PH for 2020 include breast, colorectal, cervical, and head and neck cancers. In addition, the registry captures a myriad of information that can potentially answer questions relevant to the individual cancer patient and clinicians, and hospital administrators.

Conclusion: HBCRs are an indispensable part of effective cancer control programs as they facilitate making evidence-based decisions that would result in better healthcare for Filipino cancer patients.

Keywords: Philippines, cancer, cancer registry, epidemiology

Introduction

A cancer registry is an essential part of any rational program of evidence-based cancer control.¹ Information from this database can be used to study the epidemiology of cancer and its outcomes within a group of patients with a specific cancer type (site-specific), diagnosed and treated in a particular hospital or group of hospitals (hospital-based), or living in a single geographic region (population-based).

The creation of a Philippine National Cancer Registry was mandated in the National Cancer Control Act (NICCA) of 2019.¹ This will be a population-based cancer registry (PBCR) containing incidence, prevalence, and mortality rates of cancer in the country that will allow health policymakers to study the epidemiology of cancer and, in doing so, identify gaps in local healthcare delivery and

service. In addition, worldwide cancer trends and epidemiologic data, compiled and published by the International Agency for Research on Cancer (IARC) and contributed to by 184 country registries, are also population-based, as are most national cancer registries in the world, and are valuable in understanding and controlling the disease on a global level.

Beyond studying local and global trends in cancer epidemiology through population-based cancer registration, monitoring the current status of cancer diagnosis and treatment is essential for effective cancer control and high-quality cancer care. It is best done through hospital-based cancer registration.² In Japan, for example, hospital-based cancer registries (HBCR) address the information needs of patients and physicians through 397 hospitals designated as cancer care hospitals by the Japanese government.² In Korea and India, hospital-based cancer registries are essential partners of national population-based cancer registries.^{3,4} Also, there are continuous efforts to expand the scope of registry data items essential to addressing the limitations of their national cancer registries to increase their usefulness for local and national stakeholders.³

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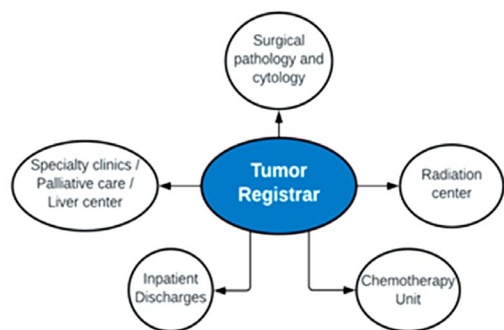


Figure 1. Hospital catchment areas where cancer patients are diagnosed or treated

Recognizing the importance of both population- and hospital-based cancer registries in the Philippine Cancer Control Program, the NICCA mandates that every hospital have a hospital-based cancer registry.¹

This paper has three objectives: (1) To discuss the challenges in the creation and maintenance of the country's first hospital-based cancer registry system (Cancer CARE Registry Philippines or CARE PH HBCR), how the system is organized, how it collects information, and its future directions in registry and research; (2) To report on the current status of the hospital membership of the CARE PH HBCR; (3) To do an exploratory data analysis of the 2020 summary data of CARE PH.

Methods

Building a database. The creation of the database required the understanding that the purpose of the cancer registry is to follow a cancer patient from diagnosis, to staging, to treatment, to cure, relapse, or into death. Throughout this journey, an updated HBCR was expected to be able to capture and document the baseline information per registrant and, with time, document the status changes and eventual outcomes.

Collaboration between a clinician and a health information technology specialist was necessary to develop important baseline definitions of cancer, how it is staged, treatment options available, clinical status definitions and definitions of outcomes of interest, and how these can be automatically derived from inputted data. This information was translated into data fields in a web-based application - the Cancer CARE Registry Philippines, or CARE PH (*Table I*).

Creating a process flow. Catchment areas, where cancer patients with a hospital- or patient identification numbers are diagnosed and treated, were identified within the hospital. Since almost all cancers are diagnosed via tissue or liquid biopsy or cytology, the Surgical Pathology Department is the main catchment area in the hospital. In addition, cancers like Germ Cell Tumors, Liver Cancer, or Brain Tumors, which do not need tissue biopsy for clinicians to diagnose and treat, had their Specialty OPD clinics as catchment areas (*Figure 1*).

Table I. Data fields in the CARE PH Application (Filled up 70% to 100% of the time and shared with central CARE PH database)

Category	Items
Patient information	Full name, sex, date of birth, hospital patient ID number, PhilHealth number, contact numbers, e-mail address, home address
Cancer diagnosis	Primary site, ICD-10 code, date of patient entry into the reporting health facility system, date of cancer incidence, details of basis for cancer diagnosis (pathology lab where biopsy was done, pathology report number, histopathologic diagnosis), cancer stage, clinic notes
Cancer treatment	Details of therapeutic or palliative procedure/s received (surgery, chemotherapy, radiation, hormonal therapy, biologic and immunotherapy) and their respective start and end dates For Z-package patients: date of admission, date of discharge, days of stay, surgical morbidities, clinic notes
Disease status	Cancer stage, Local or systemic recurrence, relapse, disease progression, partial remission, complete remission, stable disease, or death; date of disease status
Data management	Name of tumor registrar/encoder, date and time of patient record creation, name of reporting health facility, cancer registry identifier

Patients diagnosed in another hospital but treated in a CARE PH hospital were identified through logbooks in the Radiation or Chemotherapy areas or Oncology clinics within the hospital. The hospital tumor registrar goes to all catchment areas in the hospital and enters information in all required data fields in the hospital cancer registry daily. Access to the database can be done only through the hospital's local area network (LAN) and is kept secure by the hospital IT department or tumor registry office, which provides usernames and passwords to a limited number of hospital staff properly trained on data security and entry of data into the registry.

Figure 2 illustrates the flow of data from the user (the tumor registrar) to the different parts of the CARE PH Web application, all saved in the hospital database and ultimately stored in the Central CARE PH database after it is anonymized and encrypted. Data shared includes the patient CARE PH Registry number, PIN, age, date of patient entry into the database, primary cancer site, and cancer stage (*Table I*). For example, suppose the same patient goes to two different CARE PH hospitals; the central database flags the two patient records. If these have the same patient initials, birthday, and primary site, the records are counted as one in the CARE PH summary report, available on the CARE PH website (<https://careph.org>).

Staffing and Training. The Tumor Registry office of each CARE PH hospital has at least a Doctor Champion and a Tumor Registrar. The Doctor Champion is an oncologist

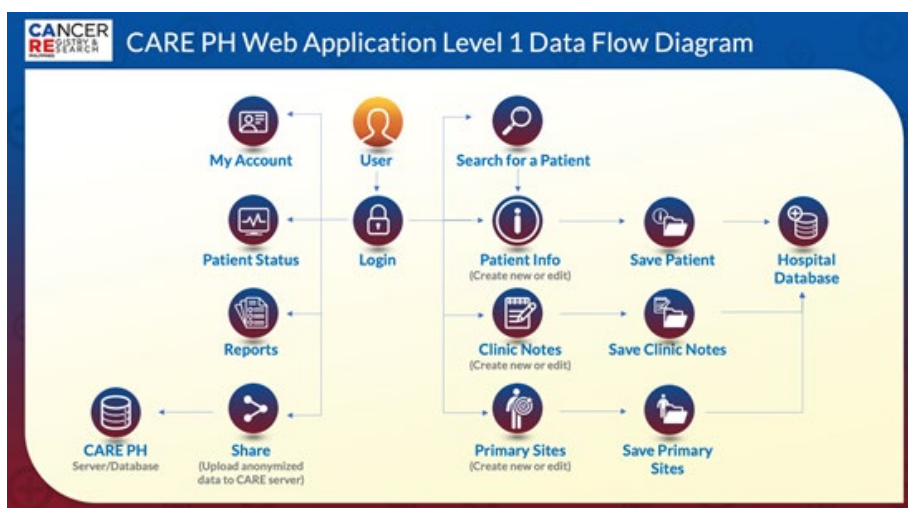


Figure 2. CARE PH Web Application Level 1 Data Flow Diagram

or general physician familiar with a cancer patient's journey from diagnosis to survivorship. The Tumor Registrar is someone who has been trained in Good Clinical Practice and data entry into the cancer registry app. She/he also makes rounds to the different catchment areas within the hospital to collect information and regularly shares the hospital cancer registry data with the central database.

Hospital Membership. The Medical or Executive Directors of the original members of the CARE PH HBCR System were approached through their volunteer doctor champions (medical oncologists) and invited to join the HBCR System. As a result, a Memorandum of Agreement (MOA) was signed between the hospital and CARE PH, which specified the roles and responsibilities of both parties.

The main responsibilities of member hospitals are to make sure that their hospital cancer registry is secure, with patients' privacy protected within their LAN, and regularly share their data with the central CARE PH database. In addition, the main responsibility of CARE PH is to make sure the data in the central database is encrypted and summarized and cannot be traced to individual cancer patients of member hospitals. Another responsibility of CARE PH is to maintain an updated website containing the summarized central database and publish an Annual Report.⁵

Funding. The Philippine Society of Medical Oncology (PSMO) and the Philippine College of Physicians (PCP) were approached as funding was needed to pay for trips to the different provinces where doctor volunteers were willing to meet up with their Medical Directors whom they helped convince on the value of having a hospital cancer registry. The CARE PH app is given to member hospitals for free.

The two individual creators of the app established the CARE PH Foundation, Inc. In addition, they invited two

other medical oncologists and a patient advocate to become members of the Board of Trustees. In its second year, CARE PH approached Philam Foundation, Inc (PFI), requesting funding and operational support for CARE PH. PFI responded by providing guidance in securing accreditation from the Philippine Council for NGO Certification (PCNC), and in becoming a certified Science Foundation under the Department of Science and Technology, and by giving an unrestricted grant for five years through its Alliance of the Philippines' Health and Advocacy or ALPHA 1 Project.

In its third year, with Securities and Exchange Commission (SEC) approval, the by-laws of the Foundation were revised to include in its objectives the conduct of ethical research studies and to change its name into Cancer CARE Registry and Research Philippines Foundation, Inc. This allowed CARE PH to initiate epidemiologic studies on specific cancer sites and start site-specific cancer registries funded by grants from Oncology Specialty Societies.

Ethics statement and data privacy. Piloted at the National Kidney and Transplant Institute (NKT) and The Medical City Pasig (TMC) in 2015, the Cancer CARE Registry and Research Philippines' (CARE PH) Hospital-based Cancer Registry (HBCR) System first submitted its proposal to these hospitals' Research Ethics Boards. The informed consent process written in the submitted protocol was approved and carried out per patient.

With the passing of the NICCA 2019, all hospitals that diagnose and treat cancer are now required to have a cancer registry and share relevant data with the Department of Health (DOH). In addition, informed consent forms of member hospitals were revised to inform cancer patients of this mandate and to affirm their willingness to comply with the law.

Table II. Hospitals with signed MOA with CARE PH in 2020

Region	Institution
NCR	1. Cardinal Santos Medical Center
	2. Chinese General Hospital and Medical Center
	3. East Avenue Medical Center
	4. Makati Medical Center
	5. Medical Center Manila
	6. National Kidney & Transplant Institute
	7. Philippine General Hospital
	8. Rizal Medical Center
	9. The Medical City Pasig
Luzon	1. Baguio Medical Center
	2. Batangas Medical Center
	3. Bicol Medical Center
	4. Bicol Regional Training and Teaching Hospital
	5. Mary Mediatrix Medical Center
	6. Naga Imaging Center Cooperative Doctors Hospital
	7. Dagupan Doctors Villaflor Memorial Hospital
	8. Palawan MMG-PPC
	9. St. Paul Hospital of Tuguegarao
	10. The Medical City Clark
	11. The Medical City Pangasinan
	12. The Medical City South Luzon
	13. Universidad de Sta. Isabel Health Services Department
Visayas	1. The Medical City Iloilo
	2. Vicente Sotto Medical Center
Mindanao	1. Cotabato Regional Medical Center
	2. Davao Doctors Hospital
	3. Metro Davao Medical Research Center
	4. Northern Mindanao Medical Center
	5. Southern Philippines Medical Center
	6. Zamboanga City Medical Center
	7. Zamboanga Del Sur Medical Center

Results

A two-year (2015-2016) pilot study served as a proof-of-concept of this HBCR System and its web-based application. The CARE PH app today has 46 data fields (Table I). Only 18 are regularly filled up by tumor registrars who are not clinicians. Clinical data, such as cancer stage and treatment given, is known only by clinicians and is not contained in a Pathology report. Thus, they are not filled in by the tumor registrar unless this information is provided to them.

There are now 31 member hospitals whose Medical Directors have signed MOAs with CARE PH (Table II). However, only 20 have contributed to the central database in the year 2020 (Table III). Member hospitals unable to share their data are those with no dedicated tumor registrar, those undergoing reorganization or change in hospital or cancer center leadership, or those whose cancer centers were closed temporarily due to the COVID-19 pandemic.

The 20 hospitals that shared their data had 9,880 new cancer registrants in 2020 (Table III). The top ten most frequently diagnosed cancers in the CARE PH Registry

Table III. Number of new CARE PH registrants per institution in 2020

Institution	Number of registrants
1. Philippine General Hospital	2,583
2. National Kidney & Transplant Institute	1,346
3. The Medical City Pasig	1,231
4. Chinese General Hospital and Medical Center	1,096
5. Dagupan Doctors Villaflor Memorial Hospital	802
6. Cardinal Santos Medical Center	669
7. Medical Center Manila	499
8. East Avenue Medical Center	456
9. Makati Medical Center	442
10. Bicol Medical Center	347
11. The Medical City Iloilo	92
12. Davao Doctors Hospital	74
13. Zamboanga Del Sur Medical Center	73
14. Palawan MMG-PPC	60
15. The Medical City Clark	50
16. St. Paul Hospital of Tuguegarao	20
17. The Medical City Pangasinan	19
18. The Medical City South Luzon	18
19. Baguio Medical Center	2
20. Bicol Regional Training and Teaching Hospital	1
TOTAL	9,880

System are Breast Cancer, Colorectal Cancer, Cervical Cancer, Head and Neck Cancer, Uterine Cancer, Blood Malignancies, Prostate, and other Male Urogenital Cancers, Lung Cancer, Thyroid Cancer, and Ovarian Cancer (Figure 3).

Table IV shows the age distribution of the top ten CARE PH cancer sites. Orange highlighted cells show the highest number of new registrants per primary site. Yellow highlighted cells show the next highest number of new registrants per primary site. Note that the table lists the age at which the cancer patients are entered into the CARE PH Cancer Registry system. Since the registry enlists only those newly diagnosed or treated in the CARE PH site, the underlying assumption is that the patient is diagnosed in a CARE PH hospital and treated in a CARE PH hospital within one year of each other.

The following cancers are most commonly diagnosed at 50-59 years of age (orange highlights): Breast, Cervical, Head and Neck, Uterine, Thyroid, and Ovarian. Note that all Female Cancers are diagnosed in this age group, with Breast, Cervical, and Ovarian cancers next highest in the younger 40-49 years of age (yellow highlights). This means that Filipinas are diagnosed with cancer at a younger age than their male counterparts. The following cancers are most commonly diagnosed at 60-69 years of age: Colorectal, Blood Dyscrasia, Prostate, and Lung Cancer. The relative number of lung cancer patients diagnosed in the CARE PH HBCR system is much lower than expected, based on the Philippine Population-

CANCER CENSUS 2020
(N = 9,880; 23 HOSPITALS; DATA SHARED AS OF END-MARCH 2021)

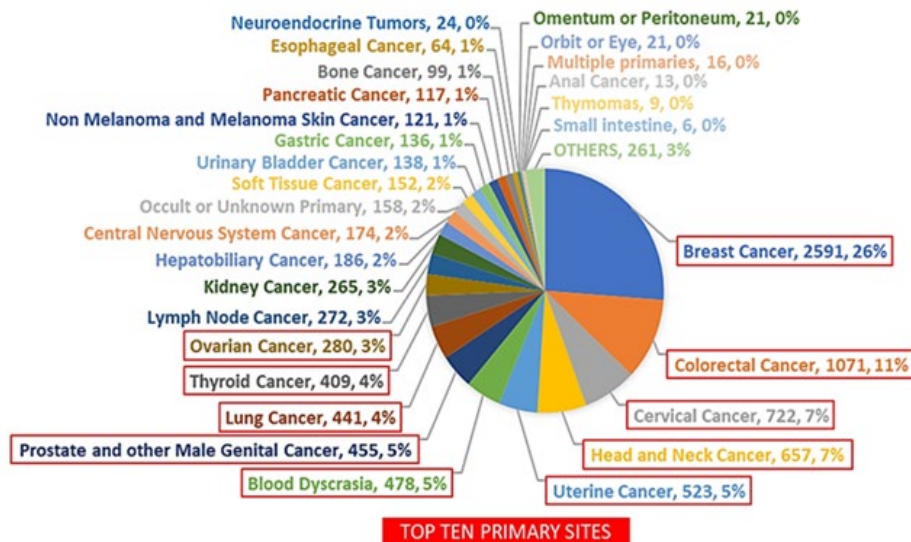


Figure 3. Frequency of primary cancer sites in CARE PH cancer census 2020.

Table IV. Age distribution of Top 10 CARE PH primary sites.

#	Primary Site	Age Range									Total
		0-10	11-19	20-29	30-39	40-49	50-59	60-69	70-79	Over 80	
1	Breast Cancer	7	2	31	258	662	753	576	228	74	2,591
2	Colorectal Cancer	3	3	16	64	133	264	357	166	65	1,071
3	Cervical Cancer	2	1	35	155	193	208	94	28	6	722
4	Head and Neck Cancer	0	8	38	68	108	182	156	70	27	657
5	Uterine Cancer	0	0	10	44	84	184	151	42	8	523
6	Blood Dyscrasia	31	24	52	43	65	82	104	41	36	478
7	Prostate and other Male Genital Cancer	3	1	7	8	9	48	193	143	43	455
8	Lung Cancer	6	0	4	13	33	86	166	100	33	441
9	Thyroid Cancer	3	6	40	74	81	96	77	24	8	409
10	Ovarian Cancer	2	8	18	28	68	85	55	13	3	280
	TOTAL TOP TEN	57	53	251	755	1,436	1,988	1,929	855	303	7,627
	TOTAL OVERALL	106	121	405	940	1,741	2,485	2,486	1,166	430	9,880
	% TOP TEN of OVERALL	54%	44%	62%	80%	82%	80%	78%	73%	70%	77%

Orange highlighted cells show the highest number of new registrants per primary site.
 Yellow highlighted cells show the next highest number of new registrants per primary site.

Based Cancer Registry System published by GLOBOCAN in 2020.

Discussion

Analyzing and using the data. A hospital-based cancer registry is patient-centered. It accompanies a cancer patient throughout their journey from diagnosis to staging to treatment and survivorship. Creating a database of these individual patients with specific cancer sites, baseline data, the stage upon diagnosis, treatment patterns, and subsequent outcomes results in a big picture that can assist individual patients in understanding their journey ahead. This helps patients

answer questions like, "How many are there like me, what stage is my cancer usually diagnosed in, what treatment options are out there and what happens to those like me with the same disease, stage, and treatment? What are the possible outcomes? What are the potential pitfalls? How can these be avoided? How much money should I set aside? How long will treatment last? What are the chances of cure?"

For the clinical oncologist and multidisciplinary team members, registry data gives a more granular picture of current practice and gaps in patient care.¹ For example, "What stage are cancer patients usually at when

Table V. Number of Blood, Kidney, and Urogenital Cancers in NKTl vs. Central Cancer Registry (2020)

2020 Cancer Registry	NKTl	Central (Summary)
TOTAL	1,346 (%)	9,880 (%)
Blood Dyscrasia	303 (23)	478 (5)
Kidney Cancer	185 (14)	265 (3)
Prostate Cancer	166 (12)	455 (5)
Urinary Bladder	60 (4)	138 (1)

diagnosed in their hospital, and therefore in their community? What strategies can be adopted to diagnose patients at an earlier stage? Is there a higher-than-average number of a specific cancer type in the hospital? How can this data be interpreted? Are better specialist oncologists found in this hospital? Do they have better teamwork?"

For hospital administrators, planning for new treatment facilities or equipment, the building of needed service areas, and staffing and training of hospital personnel and service providers are facilitated by having a cancer registry. For example, in the 2020 NKTl Hospital Cancer Registry, Blood Dyscrasia, Kidney Cancer, and Prostate and Other Male Genital Cancers make up 23%, 14%, and 12% of their total 1,346 registrants, respectively. This contrasts with 5%, 3%, and 5% of the 9,880 registrants in the 2020 CARE PH central database for three cancer types (Table V). To the hospital administration of NKTl, this validates that they are fulfilling their mandate as a DOH Reference Laboratory for Blood Disorders, as a Center of Excellence for the diagnosis and treatment of kidney and urogenital diseases, and as a transplant center for blood malignancies and kidney diseases.

Overcoming challenges

Missing data. The CARE PH Hospital-Based Cancer registry system seems to capture less lung cancer, liver cancer, thyroid, and lymphoma patients than the Population-Based Cancer Registry System, as captured by the Manila, Rizal, and Cebu Population-based Cancer Registries. In response to this observation, CARE PH plans to expand its catchment areas to include Liver Centers, Cytology Sections, and treatment areas like Chemotherapy units, Radiation oncology units, and Surgical Pathology sections of Pathology departments. If the pathology report of a cancer patient is unavailable, usually this is because the biopsy was done in a different hospital, and the patient has no copy of the results. Thus, the pathologic data fields of the cancer registry will be blank. Other data that only clinicians know, such as cancer stage, treatment given, and patient status, also have corresponding data fields in the registry, often left blank by the tumor registrar due to lack of access to this information.

To overcome these challenges, either the patient's attending physician should be the one who will enter clinical data into the registry or the tumor registrar should be given access to the patient charts. The former solution has been tried many times in past failed attempts to

require physicians to enter patient data into patient registries. However, with the Universal Healthcare Act signed into law in 2019 and its requirement for complete disease documentation before reimbursement by PhilHealth, this approach may soon be successful. The second solution, which is to give the tumor registrar access to the patient charts to extract the relevant data, is tedious and requires a second data encoder assigned to do this. Electronic medical records will be a good way to make otherwise missing data more accessible, but not all hospitals have these as most hospitals still use paper-based charts.

Hospitals' willingness to participate. Three or four hospitals have turned down the invitation to join the CARE PH HBCR. One hospital has signed a MOA with CARE PH, but with the change of leadership, has decided not to participate. A possible reason for non-participation is physician or hospital administration resistance to share data, even if it is anonymized and encrypted, even if cancer is a reportable disease, and even if every hospital is required to have a cancer registry by the NICCA Law.¹ Such reluctance is likely due to concerns regarding the Data Privacy Act.⁶ Rule V, Sec 22b of the implementing rules and regulations of the DPA, however, states that the processing of sensitive personal and privileged information is prohibited, *except when this is provided for by existing laws and regulations, provided, that said laws and regulations do not require the consent of the data subject for the processing, and guarantee the protection of personal data.*

Ten CARE PH hospitals have signed MOAs but have not begun to share their data. One reason for this is the lockdown in big cities in the country during the COVID-19 pandemic. During lockdowns, the non-essential hospital staff is asked to work from home, and cancer patients are too scared or have no means to go to hospitals. Another reason for this inactivity could be of lack of funding to hire a doctor champion and a tumor registrar.

Governance, maintenance, and funding. CARE PH Foundation, Inc. is a non-stock, non-profit, non-government organization founded by two private individuals and registered at the Securities and Exchange Commission (SEC) in 2017 using personal funding. Accredited by the Philippine Council for NGO Certification, CARE PH abides by the strict SEC Code of Corporate Governance. Funds are raised via the conduct and administration of epidemiologic studies approved by the Single Joint Research Ethics Board or individual hospitals' institutional review boards, collaborating with specialty medical societies or private companies. Fundraising is a constant challenge for any NGO. Funds are raised in collaboration with specialty societies thru unrestricted grants from private companies.

Future directions of HBCR

Monitoring the current status of cancer care is essential for effective cancer control and high-quality cancer care.² Data gathered by HBCRs give an accurate, "down in the trenches" picture of the healthcare experience of cancer

patients. Closely analyzing the data helps bridge the gaps in service and allows the patient experience to be less difficult during the most challenging part of their lives.

HBCRs can also assist in the creation of a robust population-based national cancer registry. Collecting data on all new cancer cases in the thirteen regions of the country can be facilitated by having regional hospital cancer registries. Data from a specific period can provide a framework for assessing and controlling the impact of cancer on the community.⁷ HBCRs can also be useful to the National Cancer Registry by assisting in the active case finding of newly diagnosed cancer patients.

Active case finding is also needed in site-specific cancer registries, which are now emerging in the country's research arena. For example, gynecologic cancers, blood cancers, urologic cancers, and soon colorectal, breast, and liver cancers will have registries that will be useful in establishing baseline data and monitoring outcomes brought about by site-specific cancer control programs.

Conclusion

Hospital-based cancer registration is essential in monitoring the current status of cancer diagnosis and treatment of individual patients. It is necessary for effective cancer control and high-quality cancer care on a particular hospital level and on a regional or even on a specialized nationwide cancer referral hospital level. A comprehensive and robust hospital cancer registry system can go a long way in improving the quality of cancer diagnosis and treatment in the country and contributing data to the National Population-based Cancer Registry. These, together with site-specific cancer registries now also being created and maintained, will lay the groundwork as we move forward toward better healthcare for Filipino cancer patients.

Disclosure: The authors declare that there is no conflict of interest.

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