GUIDELINES INSTITUTIONALIZING AND STRENGTHENING THE PHILIPPINE RENAL DISEASE REGISTRY (PRDR) UNDER THE DEPARTMENT OF HEALTH (DOH)

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I. RATIONALE

The Philippine Renal Disease Registry started in 1995 as a project of the Philippine Society of Nephrology (PSN) which consists of two major components namely: the Chronic Renal Disease Registry and the End Stage Renal Disease (ESRD) Registry. The Chronic Renal Disease Registry is composed of the Renal Biopsy Registry and the ESRD Registry is composed of Hemodialysis (HD), Peritoneal Dialysis (PD) and Transplant Registries.

In the year 2000, PSN entered into a Memorandum of Agreement (MOA) with the National Kidney and Transplant Institute (NKTI) with the aim of expanding and strengthening the scope of PRDR. From the year 2000 to October 2008, PRDR has been managed by the NKTI through the Renal Disease Control Program (REDCOP). NKTI provides full financial and logistical support to the Registry while PSN gives technical assistance through its officially appointed members of the Board.

In the year 2006, the implementation of the Registry was further strengthened with the linkage with the Philippine Health Insurance Corporation (PHIC) making the submission of the dialysis patients data forms from each of the dialysis center to the REDCOP office mandatory as part of the licensing and accreditation requirement. The PRDR provides useful and relevant information for direction setting, planning and policy formulation both for the national and local levels.

Since the scope of the PRDR is expanding and its uses is becoming more relevant and important to national and local health and non-health sectors' interest, there's now a need to continuously sustain and support the Registry. In line with this, the PRDR is being institutionalized within the Department of Health under the National Epidemiology Center (NEC).

II. SCOPE

The scope of the PRDR implementation includes collection and retrieval of data of ESRD patients from all dialysis units, transplant centers and other hospital facilities that are engaged in the management and treatment of kidney patients especially those with chronic kidney diseases and the ESRD patients nationwide. The following health facilities and health professionals, whether private or government, will be participating in the PRDR:

Health Facilities:

1. Hemodialysis Centers (free-standing and hospital-based)
2. Peritoneal Dialysis Units
3. Transplant Centers
4. Other hospital facilities with renal biopsy capability

Personnel:

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1. Nephrologists
2. Transplant Surgeons
3. Pathologists
4. Internists
5. Residents and Fellows in Nephrology and Transplantation
6. Nurses
7. Medical Technologists, etc.

III. OBJECTIVES

This Order is being formulated to make official the institutionalization and strengthening of the Philippine Renal Disease Registry under the National Epidemiology Center of the Department of Health. This is also aimed at formalizing the involvement of the National Kidney and Transplant Institute (NKTI) through the Renal Disease Control Program (REDCOP), as the implementing arm of the PRDR, and other health facilities mentioned under Section II of the AO as participating bodies whose roles and responsibilities are spelled out under the following sections of this AO..

IV. DEFINITION OF TERMS

1. Partnership is a voluntary agreement between two or more parties to work cooperatively and objectively toward set outcomes that can be shared for effective and efficient disease surveillance. It includes the public and private sectors, national and local government units, external and development agencies, and other stake holders in disease surveillance and response activities. The principle of shared responsibility recognizes that disease surveillance and response is the responsibility of all government sectors at all levels.

2. Privacy is the right of the patient to choose what information they will release about themselves and to whom, such information will be released.

3. Confidentiality is the obligation of the public health workers to keep information about individuals restricted only to those persons who absolutely need it for health of the community. Patients have the right to know why they are providing information, to refuse to provide information, and to expect that information will be handled as confidential.

4. Dialysis a process by which dissolved substances are removed from a patient's body by diffusion from one fluid compartment to another across a semi-permeable membrane. Currently, the two types of dialysis that are commonly in use are hemodialysis and peritoneal dialysis.

5. Patient a person admitted to and receiving care in the dialysis clinic and hospital.

6. Government hospital is a hospital operated and maintained partially or wholly by the national, provincial, city, municipal government or other political unit, or any department, division, board, or agency thereof.

7. Private hospital is a hospital privately owned, established and operated with funds through donation, principal, investment, or other means by an individual, corporation, association, or organization.

8. Institution or hospital based clinic is a clinic that operates as part of the health institution (e.g. hospital, multi-specialty clinic, etc.) and is located within its premises.

9. Free-standing clinic is a clinic/unit/center that operates independently. It may be located outside or inside the premises of health institution.

10. Training Institution is a hospital or medical facility that provides sub-specialty training for nephrology and

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transplant.

V. POLICY STATEMENTS

The PRDR shall be guided by the following principles:

1. The PRDR shall be a system that is consistent with and supportive of the technical leadership role of the DOH in the health sector and shall contribute to the achievement of the National Objectives for Health (NOH) and the Millennium Development Goals (MDG).

2. The PRDR shall comply with the guiding principles of the usefulness and applicability of its data for health planning and policy formulation, and simplicity as well as flexibility of the system for integration into other disease registries.

3. The PRDR shall recognize and adopt the principle of partnership and shared responsibility.

4. The PRDR shall ensure that privacy and confidentiality of the patient's information will be maintained.

5. The Department shall be the owner of the PRDR data. It will, however make the PRDR data/ information available and accessible through REDCOP based on set guidelines and protocols.

VI. IMPLEMENTING MECHANISM

The PRDR includes the following registries: the ESRD Registry which consists of data of patients on hemodialysis, peritoneal dialysis and data of patients who underwent transplant operations and the Chronic Renal Disease Registry which consists of data of patients with renal biopsy. The scope of the PRDR will be expanded as the need arises for the interest of the public and the health sector. To ensure effective and efficient implementation; to be able to generate the expected results from the yearly collection of data from all sources and, to be able to maximize utilization of output from the Registry, the following guidelines will be followed.

1. Roles and Responsibilities of the offices concerned

a. National Epidemiology Center – Department of Health (NEC – DOH)

- Provides overall supervision and allocates annual funds and logistic support to REDCOP-NKTI for the overall management and implementation of PRDR.
- Ensures that PRDR results are utilized for national health planning and policy formulation;
- Analyses, utilizes and disseminates registry results through officially designated NEC personnel;
- Gives official designation/authority to NKTI-REDCOP to coordinate with the Center for Health Development Offices (CHDs) activities pertaining to training/orientation, data, gathering, verification, and consolidation of reports from dialysis units, transplant centers (through officially designated transplant coordinators) and hospitals (for the kidney biopsy registry through the attending physician);
- Requires REDCOP-NKTI to submit reports NEC-DOH on a semi-annual basis or as needed;
- Ensures efficient and effective implementation of the PRDR by making all lines of communication accessible to the implementing arm;
- Monitors and evaluates PRDR implementation and data management;
- Creates and chairs adhoc working committee and calls quarterly meeting for updates, feedback and resolution of issues and concerns in the implementation. This adhoc working committee shall receive, study and/or review expert advise/s from official representatives of concerned agencies and other stakeholders for appropriate action and decision and/or recommendation;
- Spearheads the appraisal of research proposals and projects on Renal Disease Management, Prevention and Control.
- Designates official point person for PRDR

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b. National Kidney and Transplant Institute-Renal Disease Control Program (NKTI-REDCOP)

- Maintains privacy and confidentiality of patients information;
- Designates/hires technical people to assist in report preparation
- Performs the over all management and implementation of the PRDR as mandated by the National Epidemiology Center-Department of Health
- Provides technical support and direction on the proper reporting form of PRDR data
- Submits to DOH semi-annual reports to NEC or as needed by the Secretary of Health
- Submits biannual accomplishment and audited financial reports to the DOH finance service and copy furnish NEC.
- Submits to DOH reports in publishable form annually in addition to the annual PRDR report.
- Liaises with other agencies, GOs and NGOs as necessary to improve PRDR operations and data quality
- Attends quarterly NEC meeting or as necessary for updates on registry and other matters

c. Bureau of Health Facilities and Services (BHFS)

- Pursuant to Administrative Order (AO) No. 163, s. 2004, Revised Rules and Regulations Governing Registration, Licensure and Operation of Dialysis Clinics in the Philippines", enforces the registry of patients of all dialysis units in the country with the Renal Disease Registry that is being implemented by REDCOP.

2. Participating Parties and Offices

a. Dialysis Clinics/Centers/Units

- Health facilities that provide either peritoneal dialysis or hemodialysis treatment to ESRD patients and serve as the sources of data forms of dialysis patients.

b. Hospital Facilities including Training Institutions

- Hospital facilities and Training Institutions that cater to patient's needs specifically renal work-up and treatment including renal biopsy and transplantation operation.

c. Centers for Health Development (CHD)

- Regional Office under the DOH with officially assigned Coordinators for REDCOP. These Coordinators collect/retrieve the data forms of dialysis patients from the dialysis centers/clinics/units, and collate them for submission to the REDCOP Office.

d. Philippine Society of Nephrology (PSN)

- The specialty society that provides technical/specialty assistance in the preparation of the annual report.

e. Philippine Health Insurance Corporation (PHIC)

- The Office that enforces the participation of all accredited dialysis clinics, hospital-based or free-standing pursuant to Circular No. 06 s. 2006 (Annex A)[*]

3. Operational Standards

The detailed implementing Guidelines are reflected in the Manual of Procedures of the PRDR 2006 (Annex B).

4. Budget Allocation

The DOH shall release funds for the PRDR yearly operations, in accordance with the budget proposed by NKTI-REDCOP and approved by NEC.

The annual fund shall be used for the payment of the PRDR operation such as transportation and

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communication expenses, supplies and materials payment of salaries of contractual personnel, and honorarium for consultants, and overall PRDR operations at the regional level. The fund shall be charged to the National Epidemiology Center under GOP Fund Source A. III.b.I.

Any approved expansion of the scope of the Registry will be provided with corresponding budget allocation by the DOH.

5. Reporting

The REDCOP office as the main implementing arm of the PRDR will be submitting an annual report to the DOH-NEC every first quarter of each succeeding year. Quarterly updates on the status of the implementation and the budget utilization will likewise be provided to NEC by the REDCOP during the first month of the ensuing quarter of each year.

6. Monitoring

Monitorin g of the details of the operations will be done by the REDCOP office headed by the program manager while the NEC headed by the Director will take charge of the semi-annual supervisory assessment for the DOH.

Administrative and financial problems, issues and concerns arising from the implementation of the PRDR will be brought to the attention of the NEC Director and officially designated coordinator for discussion and appropriate action.

VII. REPEALING CLAUSE

Any existing order not consistent with any of the provisions provided herewith is considered repealed or superceded by this AO.

VIII. EFFECTIVITY

This order will take effect upon approval and fifteen days upon publication in the official gazette or newspaper of general circular.

Adopted: 27 May 2009

(SGD.) FRANCISCO T. DUQUE III, MD, MSc
Secretary of Health

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[*] Not Filed with ONAR.

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