

**[DOH ADMINISTRATIVE ORDER NO. 2009-0012,
May 27, 2009]**

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

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:

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 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.