

## Chapter XI

# Patient Information Systems

### OVERVIEW

The patient information system is designed to ensure that a standardised, effective and efficient system for data collection, collation, monitoring, and feedback is in place to facilitate programme implementation, ensure good quality care, and achieve good patient/programme outcomes. The specific functions are:

- To register patients utilizing a standard patient record
- To collect relevant clinical care information at baseline and subsequent follow-up visits to monitor progress of patients
- To monitor adherence to treatment
- To monitor adverse drug events
- To collect other clinical, laboratory, and non-clinical data that will be useful for programme monitoring at local, provincial and national levels

The patient information system will need to be developed as an integral part of existing health information systems in South Africa. The system will need to be integrated into existing data collection systems, and will be standardized across all facilities in the programme. Basic data should be collected at the facility level, analysed for local use, and passed on to the provincial and national levels for programme monitoring and evaluation.

### BACKGROUND AND RATIONALE

The national health information system is made up largely of three sub-systems: hospital information systems, a district health information system, and a disease notification system. All but the latter should be adapted for the ARV treatment programme.

#### Hospital-Based Systems

Patient information systems in hospitals vary across facilities, ranging from large, sophisticated systems such as Medicom and Meditech, through homegrown systems such as the Patient Administration and Billing system (PAAB), to manual paper-based systems.

The systems share a certain degree of similarity, but are not always compatible. Although there has been an attempt to standardize these systems, this has not been fully achieved.

The following is a listing of the information systems that are currently in place in the provincial hospitals:

- PAAB is implemented in a number of hospitals in Gauteng, Mpumalanga and North West.
- Medicom is implemented at 9 hospitals and 5 clinics in Gauteng and at Inkosi Albert Luthuli hospital in KwaZulu-Natal.
- Delta 9 is implemented in Limpopo and clinics in Eastern Cape.
- Systech is used in 3 academic hospitals in the Western Cape.
- Oasis is used in 6 hospitals in the Northern Cape.
- Meditech is used in 3 hospitals in the Free State.

### **District Health Information System**

The District Health Information System (DHIS) has been developed primarily to provide core information for primary health care administration. It collects basic facility information, including rosters of hospitals, health centres, and clinics, as well as a number of specific modules. A Hospital Module contains information on utilisation, bed occupancy and length of stay. A PMTCT Module and a Patient Module have been developed over the past year.

### **APPROACH**

The ARV treatment programme will modify the PAAB module as the standard for data collection. Provinces may adapt this module onto their existing systems, provided this adaptation collects the standardized information. Where the use of electronic systems is still limited, or where the electronic PAAB module cannot be integrated into existing hospital information systems, a paper-based version of the modified PAAB system will be used. These paper-based data will be converted into an electronic file, to be used for monitoring and evaluation at provincial and national levels. As the programme is implemented, paper-based systems will ultimately need to be replaced entirely by electronic records. A standard patient information form and basic dataset will need to be adapted in all provinces to ensure standardisation.

## **Data Modules**

The major component of the modified PAAB form will be known as the "Patient ARV Treatment Report Form," and will contain the following unique modules. These modules are designed to contain the minimal essential information necessary to ensure good patient outcomes and efficient programme administration.

### ***Patient registration***

All patients entering the programme should be registered using the national identification number (ID), surname and date of birth. The ID number will be used as a patient identifier across all systems at every level of health care and in any province to avoid duplication and repetition of procedures. The system should be able to identify nationality or residence status as well as medical insurances/schemes.

Demographic data contained in the Patient Registration Form include:

- Names and surname
- Address/telephone
- Date of birth: dd/mm/yy
- Identification number
- Gender
- Marital status
- Next of kin
- Population group
- Employment
- Education
- Name of local and district municipality
- Province
- Citizenship/Residence status
- Facility

### ***Medical history/examination***

At the first visit following registration, a form will be administered to capture a patient's medical history, including previous illnesses, hospitalisation, date of HIV diagnosis, date

and location of VCT, current medications, symptoms, and ARVs taken previously, including nevirapine. For women, current or planned pregnancy, access to PMTCT services and access to contraceptives will be assessed.

A baseline examination of patients will also include vital signs, weight and details of any abnormalities of the eyes, oropharynx, lymph nodes, lungs, heart, abdomen, extremities, etc. This information will be captured in the baseline medical history/examination form.

At each follow-up clinic visit, an abbreviated version of the medical history/examination form will be completed. It will include:

- Vital signs
- Interim medical history, including: illnesses, hospitalisations and visits with specialists
- Current ARVs prescribed, if any
- Assessment of ARV adherence, if taking ARVs
- Assessment of ARV side effects, including: rash, weight changes, abdominal pain, and nerve pain in the hands and feet
- Allergies and current non-ARV medications

If the patient is admitted to a hospital or treated in outpatient specialist clinics, a medical history/examination form should be completed there as well. Upon completion of treatment or hospital discharge a summary record should be generated automatically by the PAAB system to enable verification by medical records staff and enable completion of any missing information.

***Laboratory and other diagnostic information***

The results of laboratory tests and other diagnostic evaluations performed either at the implementation site or at designated laboratories should be captured as part of the patient record. At a minimum, the patient information system should capture the results of the CD4 cell count, viral load, and other basic tests, including those used to identify potential adverse reactions to ARVs. The frequency of these tests will be determined by the treatment protocols for ARV management. The NHLS will also retain patient laboratory information as part of its laboratory information system (LIS).

***Pharmacy and pharmacovigilance***

Data captured as part of the patient medical record will support drug dispensing for inpatients and outpatients. This part of the patient record will interface with a separate pharmacy database, which will provide for entry of prescriptions and medication orders at outpatient clinics or wards. On entry of prescription, the pharmacy database will display other drugs that have been prescribed to a particular patient. The system will need to have a controlled procedure for the authorization of all issued drugs and will maintain a separate register or controlled drugs and narcotics.

For inpatients, the National Health Care Management Information System (NHC/MIS) should maintain patient medication profiles and prepare medication administration schedules with days, times, and dosages. It should also check for allergies or sensitivities, possible drug interactions, contraindications, over dosages, and special instructions, taking into account the route, dosage, forms and times of administration. Information on adverse drug events should be captured.

Specific data elements collected in the pharmacy database will need to be coordinated with the Pharmacovigilance unit (see Chapter XIII, *Pharmacovigilance*), and will include:

- Medications
- Date treatment was commenced
- Date treatment was terminated
- Reasons for treatment termination: (e.g. patient defaulted, patient decision, patient lost to follow-up, adverse drug reactions, patient died)
- Adverse drug reactions
- Treatment adherence information

The system should, on completion of the summary or abstract of treatment details, have the tools to render the record non-modifiable. From then on, the NHC/MIS should maintain that as part of medical history, accessible to authorized users.

**Service utilization**

The modified PAAB system will have to permit scheduling of appointments and follow-up visits. The appointments may be given either for a specified time or for a time-bracket and

should enable a conscious overbooking and the handling of emergencies. The system should be able to detect appointment conflicts, enable rescheduling of appointments and hospital clinics, cancellation of appointments, and track non-compliance with scheduled visits.

The system will need to fully support the processing of admissions, discharges and transfers of inpatients, including emergency admissions. Discharges should be entered either at the nurse's station or the medical records office. The system should generate a discharge summary, especially for patients that were referred from other levels. Visits to specialists, laboratories and general clinics will need to be recorded, with recognition of first visit and subsequent visits. The system should permit recording of actual/scheduled information along with defaulters to ensure production of accurate monthly utilization reports.

### **IT Development**

As the programme moves beyond the initial phase, and the number of sites increases, there will be a significant expansion of reporting points requiring investment in health information infrastructure to upgrade electronic information systems, computer hardware and software, and to enable effective interface with laboratory and pharmacy information systems.

### **ADMINISTRATIVE STRUCTURE**

Within each facility, a clerk should complete patient registration, and the clinician or nurse attending the patient should complete clinical records. At each additional point of contact in the facility (laboratory, pharmacy, etc.) a patient-linked record will need to be completed and integrated into the patient's file. If paper forms are used, a data clerk should complete electronic entry. Each facility will have a clear information flow protocol, and checks to ensure that all records pertaining to the programme are collated at the close of each day. One individual at each facility should be assigned as the data/M&E officer to conduct checks and ensure completeness of data entry.

Data entry manuals and guides for data entry and completion should be developed at the national Strategic Management Team (SMT) and made available to facilities.

At the district level, a single M&E officer should ensure that data from each facility are collated and completed. Abstracts of these data should be made available to facilities, to the provincial office, and to the national office. The information to be passed back to facilities, the districts, and the provinces will be established by the Department of Health as part of the Monitoring and Evaluation activity (See Chapter XII, *Monitoring and Evaluation*). A succinct newsletter or ‘monitor’ will be developed and circulated to all participating facilities and provincial offices as a feedback mechanism to track progress in the programme. The M&E office will be responsible for all aspects of the data collection and management process.

Finally, simple modifications of the DHIS Hospital, PMTCT and Patient Modules will need to be made to collect information on utilization rates, ARV distribution, and other information relevant to the ARV treatment programme administration not obtainable directly from the modified PAAB patient record system.

## **PROGRAMME ASSESSMENT**

The success of the patient information system initiative depends on strong coordination at the central level (via the Cluster of Health Information, Evaluation and Research and the NHISSA committee), collaboration with the provincial health information teams, and the availability of adequate resources including personnel, training time and equipment at the district and service point level

Progress of the patient information programme will be assessed using the following measures:

- Number (and percentage) of sites using the national system
- Number (and percentage) of sites reporting complete minimum data set
- Speed and accuracy of reporting
- Progress toward migration to national system
- Progress toward complete integration of existing systems.

The Cluster of Health Information, Evaluation and Research will conduct an evaluation at the national level.