HIV PATIENT MONITORING AND CASE SURVEILLANCE

USING UNIQUE PATIENT IDENTIFIERS FOR PERSON-CENTRED HIV PATIENT MONITORING AND CASE SURVEILLANCE

2017

World Health Organization

The guidance and recommendations on the use of unique patient identifiers in the 2017 WHO *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance* should be adopted and customized to fit the specific setting of each country and programme; most importantly, to provide the highest possible quality of patient care, as well as to support programme management.

ASSESS CURRENT HEALTH INFORMATION SYSTEMS USING A SITUATION ANALYSIS TOOL (ANNEX 3.5.2)

The first step in developing a pathway for implementing unique identifiers is to carry out an analysis of the status of health information systems in the country. This provides core information that can be used to describe and define the main options and best approaches to beginning the transition from paper-based to electronic individual records, and the introduction of unique identifiers. The situation analysis should assess the following elements:

- **Programme data use**

  – This should form part of a wider review of patient data, HIV case reporting and programmatic use of data, assessing the major country databases, how they are linked and used; and

  – How the data generated by information systems are being used for planning or evaluating the impact of interventions.

- **Data security and confidentiality**

  – Assess existing privacy, confidentiality and security laws, policies, regulations and guidelines, and their implementation and enforcement in the health sector, both private and public, with particular reference to issues of privacy, security, data collection, data standards, access, data ownership, storage, transfer, use, disposal and stewardship.

  – Assess databases and systems across health and disease programmes, and how they can be strengthened, secured and used in an integrated manner.

  – Consult with patients and groups affected by data use on the benefits and risks (including health workers, patients and key population groups).

- **Data capacities and processes**

  – Identify capacities and processes for collection of health information in key health services, including those that present the best opportunities for change.

  – Provide an inventory of the forms used, and data collected and reported at health facilities.

- **Physical and human resources**

  – Assess the electricity, telephone and Internet connectivity of health facilities at district, subnational and central levels.

  – Assess the availability of computers, staff computer skills and facilities with electronic medical or health records.

- **Assess existing unique identifiers and options**

  – Provide an inventory of existing health identifiers used by programmes, facilities, insurance providers and other relevant stakeholders.

  – Assess wider national and insurance identifiers, their acceptability and use.

- **Policies and perceptions**

  – Assess public perception of unique identifiers, electronic records, popular conceptions or misconceptions, as well as issues of trust and buy-in.

  – Review country policies on the use of unique identifiers.

- **Identify the risks and benefits** of and options for transitioning to unique identifiers and electronic health information systems.

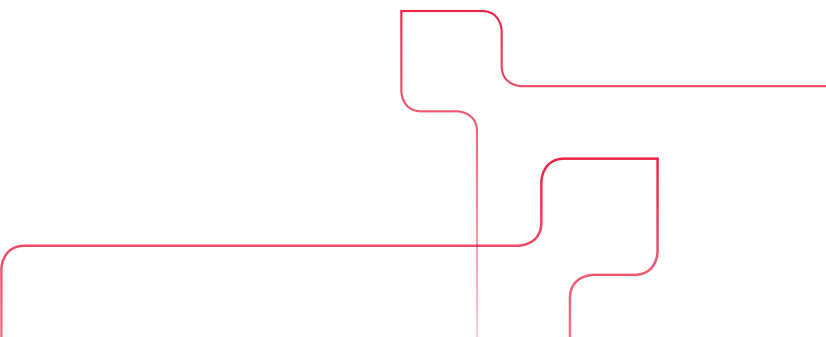- **Assess investment needs in terms of capacity, human resources and finances.**

The results of the situation analysis should provide a snapshot of the health information system, the resources being invested in health information (including software, hardware and human resources), and an overview of the laws, policies and practices concerning the collection, storage, analysis, security and use of health information. The analysis should also provide direction regarding the best place to begin and the approaches needed to further develop the information system. *WHO provides a situation analysis tool for the implementation of unique identifiers.*

STAGED IMPLEMENTATION OF UNIQUE IDENTIFIERS AND ELECTRONIC PATIENT RECORDS

Implementing person-centred monitoring involves the progressive transition from name- and paper-based individual records and registers maintained at health facilities and aggregate reporting of services to an electronic record coded with a unique identifier. This transition may be undertaken in three broad stages:

- **Early stage:** switch from name-based records to unique identifiers associated with a single individual in a paper-based health record system;

- **Middle stage:** move to the widespread use of unique identifiers and the deployment of an electronic data system with a mixture of online and offline elements; and

- **Advanced stage:** patient data are linked by unique identifiers in a fully online electronic health information system linked across services, facilities and community care.

The systems required to support the use of unique identifiers increase in complexity, depending on the level of implementation, while the benefits also increase as the use of unique identifiers is expanded to the national level (Table 1).

TABLE 1. BENEFITS AND RISKS OF UNIQUE HEALTH IDENTIFIERS

Benefits and risks	Facility level	Programme level	Country level
For person	1. Improved continuity of care 2. Anonymity of health records	1. Easier transfer of treatment when a person moves from one service or facility to another	1. Improved linkage of HIV and health services 2. Easier reimbursement through health insurance
For programme	1. Better linkage of testing and treatment, and to community care 2. Need to invest in a secure data system	1. Easier management of loss to follow up 2. De-duplication of records 3. Security of data records	1. Better management of stocks of drugs and diagnostics 2. Improved planning 3. Sustainability and open access of system

WHO provides a generic development pathway for implementation of unique identifiers and electronic patient records in the early, middle and advanced stages, based on the following six steps:

- person identification: assigning and using unique identifiers;

- investing in databases and interoperability;

- confidentiality and security;

- data analysis, quality and use;

- transition from paper to electronic systems; and

- sustainability of programme improvements.

Implementation should also be based on country examples of models of unique identification that have worked, and that show individual and programme benefits. *WHO provides illustrative examples of country experiences with progressive implementation, based on a tiered approach.*
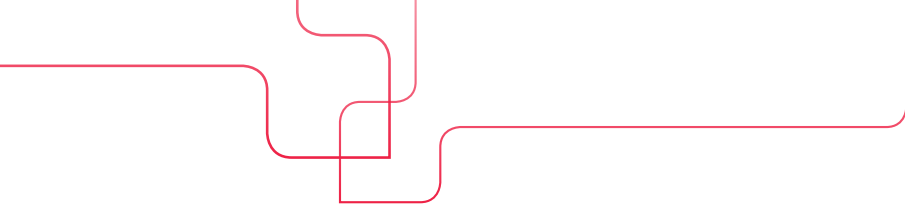
DATA USE FOR PROGRAMME IMPROVEMENT

When unique identifiers and electronic data systems are in place, used and progressively linked to national health and social systems, countries should invest in improved security and use of the data for programme improvement. This includes:

- investments in the security and robustness of databases, safeguards, and increased linkage and interoperability of data systems at facility, programme and national levels;

- investment in human resources, data use, open access policies, dashboards, feedback and analytical capacity, which are critical for the use of data for programme improvement; and

- documenting and costing the benefits and risks of programme improvement to support the case for medium-term sustainability.

TECHNICAL BRIEF

HIV CASE
SURVEILLANCE