

PEACE, PROSPERITY AND
REGIONAL INTEGRATION



REGIONAL HEALTH DATA SHARING & PROTECTION POLICY



BACKGROUND

THE INTERGOVERNMENTAL AUTHORITY ON DEVELOPMENT (IGAD)...

...is a regional trade bloc that seeks to "ensure that peace and stability prevail in the sub-region so that economic development can take place" and "contribute towards alleviation and mitigation of humanitarian crisis through long term strategies and response to acute crises."

IGAD's core mandate includes fostering integration and cooperation among Member States and addressing the health concerns of cross-border mobile populations, internally displaced people, and refugees.

The IGAD Member States include Djibouti, Eritrea, Ethiopia, Kenya, Somalia, South Sudan, Sudan and Uganda.

DATA SHARING & PROTECTION...

...is defined as the safe, secure exchange or transfer of information, including health and other sensitive data, between individuals or entities.

Data sharing and protection improves healthcare service delivery and enhances public health planning.

THE REGIONAL HEALTH DATA SHARING & PROTECTION POLICY...

...is a framework designed to help Member States implement data sharing and privacy policies in line with international best practices.

THE PROBLEM

why do we need a data sharing & protection policy?

WHEN THERE IS **NO DATA SHARING & PROTECTION, IT HARMS:**



PATIENTS

Personal health information should always be confidential. If data is not shared securely, individuals' private information could fall into the wrong hands where it can be used to harm the individual.

DISEASE PREVENTION



Disease knows no borders. If there is an outbreak in one country, it can affect a whole region. Governments can only protect the populations they serve if they have the necessary information, including data from neighbouring countries.

WHEN THERE **IS DATA SHARING & PROTECTION, IT HELPS:**



PATIENT CARE

When data is shared between health facilities, health workers have the full picture of a patient's health history and are able to treat them more effectively. This means healthier individuals and communities.



GOVERNMENTS

The adoption of a health data sharing and protection policy enables governments to effectively plan, allocate resources and make decisions. It also enhances collaboration between Member States, which results in shared learning, support, and integration of health interventions, as well as accelerated development of health information systems (HIS).

CONTEXT

of health data sharing & protection in the IGAD region

COVID-19

The COVID-19 pandemic has demonstrated that preventing disease also prevents economic hardship. We have also seen that an outbreak in one country will likely affect its neighbours. The more data that is integrated and analysed on a regional level, the more effectively governments can plan and prevent the spread of disease. Effective data sharing across borders gives national governments the tools to improve national health planning, which can save both lives and livelihoods.

CROSS-BORDER MOBILE POPULATIONS

Cross-border mobile populations (CBMPs) are groups of people who (by choice or otherwise) cross borders on a regular basis. These include truck drivers, migrants, sex workers, traders, victims of human trafficking, asylum seekers, and pastoralists. One of the challenges they face is the lack of secure data sharing between health facilities in different countries.

SUSTAINABLE DEVELOPMENT GOALS

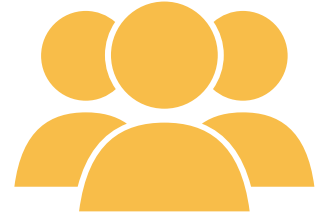
Health data sharing and protection serves as a tool to move IGAD Member States closer to achieving Sustainable Development Goal (SDG) 3, “Ensuring healthy lives and promote well-being for all at all ages” and the achievement of Universal Health Coverage (UHC).

ROLES

who is involved in health data sharing & protection?

WHO IS A DATA SUBJECT?

Anyone whose data might be requested, collected or shared. In other words: everyone!



WHO IS A DATA CONTROLLER?

The person responsible for deciding why and how to process health data, including making sure data sharing and protection principles are followed.

They could be a frontline health worker who is seeing a patient, a government collecting data from their citizens, or a private insurance company determining the health risk of a customer.



WHO IS A DATA PROCESSOR?

The person responsible for processing personal health data on behalf of the controller. They must follow the guidelines put in place by the data controller.

They could be a health information technician managing records at a clinic, a government official processing data that has been received from citizens, or a nurse sharing data with an insurance company.



PRINCIPLES

of data sharing & protection

PURPOSE & RELEVANCE

Only data that is necessary and relevant for a defined and specific purpose should be collected.

LEGITIMACY, TRANSPARENCY & CONSENT

Data controllers and processors should collect, process, and share data in a transparent and legitimate way, including obtaining consent from the data subject.

CONFIDENTIALITY & SECURITY

Data should be protected from loss, damage, destruction, and unauthorized access or use.

SHARING & TRANSFER

When data is transferred, it should be clear why it is being shared and who is involved. It should also be done in a way that keeps the data private and secure.

ACCESS

No matter where data is being stored, there should be restrictions and rules governing who is allowed to access it and for what purpose. Data subjects should have access to their own data.

QUALITY

In order for data to be useful, it must be quality data. This means it needs to be accurate, complete, consistent, valid, unique, and timely.

RIGHTS

of the data subject



WHAT ARE YOUR RIGHTS AS A DATA SUBJECT?

1) INFORMATION & ACCESS

You have the right to know why your data is being collected, how it will be used, and who it will be shared with. You also have the right to access your own data.

2) PORTABILITY

You have the right to request the transfer your own data, whether to a medical clinic or for your own personal records.

3) RECTIFICATION & ERASURE

If your data is inaccurate, incomplete, questionable, unlawful or outdated, you have the right to limit its access, or have it corrected or erased.

4) OBJECTION

You have the right to be informed before your data is shared and you can object to the processing or sharing of your own data.

EXCEPTIONS

The only situations where these data rights do not apply include:

- When the rights, freedoms, interests or protection of the general public are at risk.
- When the data is already publicly available.
- When the data needs to be shared for legal or regulatory reasons.

RESPONSIBILITIES

everyone has a part to play

CITIZENS

Keep up to date on your rights. Be actively engaged in making sure that your health data is protected and shared safely.

GOVERNMENTS

Adopt strategies and policies that support effective data sharing and protection, working with other IGAD Member States to promote coordination across borders.

PRIVATE SECTOR

Actively support and participate in government efforts to create and implement a health data sharing and protection policy.

HEALTH FACILITIES & FRONTLINE HEALTH WORKERS

Collect, process and share data in line with the data sharing and protection principles and the rights of data subjects.

IGAD

Support Member States to implement health data sharing and protection policies, as well as providing guidance and facilitating coordination between countries.