



**MEDICI  
CON L'AFRICA  
CUAMM**

Doctors with Africa

## DATA PROTECTION POLICY

Revision No. 1 -		
Prepared by	Verified by	Approved by
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## Objectives and Scope

### **I. Policy on protection of Personal Data of Persons of Concern CUAMM (introduction)**

As a medical international organization, 'Doctors with Africa, CUAMM' (simply namely CUAMM) collects and uses data of its beneficiaries and patients to analyses and improve services in the local hospitals where it gives its support. In addition, the organization uses and transfers its data for different purposes such as monitoring and evaluating the program, advocacy and research. Confidentiality and the respect of the patients are the heart of the CUAMM medical practices and are central for maintaining the trust and the integrity between the beneficiaries and the organization.

CUAMM works with neglected populations, on neglected diseases and in very specific contexts for which important knowledge gaps exist including adapted health models, strategies and medical inventions, drugs, vaccines and diagnostics.

CUAMM most of the time collects aggregated data from partners such as hospitals, health centers or other health facilities or Local Governmental Authorities. This is because the aim of CUAMM is to strengthen the Health system by analyzing Public Health data to address gaps and weaknesses and to develop strategies to improve the services given to the population.

In this policy CUAMM ensures adequate data protection guaranteeing medical confidentiality and privacy to avoid any failure to protect data that may threaten the actors' reputation, putting its staff and beneficiaries at risk.

In respect to the fundamental principles of data protection, CUAMM is committed to using Personal Data of its beneficiaries and its employees in compliance with their responsibilities under the policy on protection of Personal Data of persons of concern CUAMM and the law, including the EU General Data Protection Regulation ("GDPR") 2016/679.<sup>1</sup>

### **II. Terms and definitions**

1. **'Beneficiaries'** means persons that directly or indirectly benefit from the services offered by the CUAMM;
2. **'Consent'** of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her;
3. **'Data Controller'** means the CUAMM Staff Members, usually the Country Manager who determines the purposes and means of the processing of personal data;

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<sup>1</sup> Despite the data being collected outside of the European Union, the GDPR applies to the data processing by virtue of its Article 3(1), according to which the GDPR 'applies to the processing of personal data in the context of the activities of an establishment of a controller or a processor in the Union, regardless of whether the processing takes place in the Union or not'.

4. **'Data recipient'** means any CUAMM Staff Member, which processes personal data on behalf of the controller;
5. **'GDPR'** means General Data Protection Regulation - EU Regulation 2016/679;
6. **'Personal data'** means any information relating to an identified or identifiable natural person; an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;
7. **'Processing data'** means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organization, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;
8. **'Personal data breach'** means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorized disclosure of, or access to, personal data transmitted, stored or otherwise processed. An example of the personal data breach could be the unauthorized disclosure or the loss or the theft of personal data;
9. **'Third party'** means a natural or legal person, public authority, agency or body other than the CUAMM staff member, controller, processor and persons who, under the direct authority of the controller or processor, are authorized to process personal data.

### III. The Principles

All CUAMM personnel has to respect and apply the following principles when processing personal data:

- **"Do no harm" principle**: Inappropriate collection, unauthorized use, disclosure of, or access to, patient or community data, may result in harm to the very individuals and populations CUAMM aims to assist, CUAMM staff or CUAMM's humanitarian action; especially when the data is highly sensitive (for example, data relating to violence, abuse, coercion and deprivation). In practice, risks may range from physical, mental, dignitary, financial, political and legal harm or threats of harm, discrimination, social marginalization, and stigmatization, and are often not foreseen by the individual soliciting the information, or the person providing it. For example, in certain situations, people providing information may face reprisals regardless of what information is shared, merely for sharing data.
- **Lawfulness Principle**: CUAMM should always have a valid legal basis for processing the data.
- **Principles of fairness and transparency**: CUAMM should always be identified as a collector of the information and data of the beneficiaries, clarifying the purpose of processing and using their data.
- **Purpose limitation**: Cuamm is committed to ensuring to not reuse the data collected for other purposes.

- **Principles of necessity and proportionality**: the data collected should be necessary and proportionate used to the purposes for which it is being processed. They should not exceed that purpose identified.
- **Accuracy principle**: the data should be recorded as accurately as possible
- **Storage limitation**: the data collected should not be kept indefinitely.
- **Principles of integrity and confidentiality**: it should need to maintain the confidentiality of personal data of the beneficiaries of concern at all times, even after the data are no longer used by the CUAMM.
- **Accountability**: the Data controllers should be responsible for and able to demonstrate compliance with the principles stated above.

#### IV. **CUAMM commitment**

##### **Lawfulness Principle:**

- The data collection used or transferred is necessary to provide healthcare services to the beneficiaries of the organization;
- The data collection used or transferred is necessary to provide vital interest to those assisted, even if it is not provide direct health assistance;
- The processing of collection of personal data is given by the **Consent** of the beneficiaries, clearly indicated by a statement or by a positive action of the beneficiaries that has to be aware of the consequences of the use of data;
- Where the collection of personal data is given to a child under the age of 18, the consent of legal guardian of the child has to be obtained.

##### **Principles of fairness and transparency**

- CUAMM provides information about the Data of the local beneficiaries using clear and plain in their own language by the actors' cultural mediators or in another form comprehensive for the persons, avoiding misunderstanding;
- CUAMM provides to inform the beneficiaries the specific purposes for which the data are collected and will be used.

##### **Purpose limitation**

- The data provided by CUAMM needs to be collected for specific and legitimate purposes. The data have not been reused for other incompatible purposes outside the scope of the organization. If the organisation decides to use the data outside the scope of the organisation, it needs the subjects' explicit consent.

##### **Principles of necessity and proportionality**

- All data collected by CUAMM should be necessary and proportionate to the scope of the organisation, respecting the interest and the personal rights of the beneficiaries.

##### **Accuracy principle**

- CUAMM undertakes to record and collect data with accurate instruments, updating to ensure that individual cases are traced and followed-up through the years.

##### **Storage limitation**

- The required storage of the data will be for the time needed to manage the data from the date of the creation.

#### **Principles of integrity and confidentiality**

- CUAMM undertakes not to disseminate recorded data even when the beneficiary is no longer concerned to the organisation. The organization will implement all the necessary technical and organizational measures to ensure that the data will not be lost, stolen, etc

#### **Accountability**

- In order to ensure accountability and supervision for the process of the data of the beneficiaries, CUAMM will take any reasonable step for collecting data in accordance with its policy and the law.

### **V. Data Subject Rights**

The beneficiaries where their data are collected have the following rights:

- Right to withdraw consent at any time to the processing of data: the beneficiaries shall have the time to withdraw his or her consent at any time. Before the consent, the beneficiaries have to be informed about the possibility of the withdrawal.*
- Right to be informed:* according to the transparency principle, the beneficiaries are needed to be informed in writing or orally regarding data processing;
- Right to access:* the beneficiaries can request information about CUAMM holds about its data;
- Right to correction and deletion:* the beneficiaries may request the correction or deletion of personal data which are considered inaccurate, unnecessary or excessive;
- Right to restrict processing:* the beneficiaries may ask to CUAMM to no longer continue to process their data in certain ways
- Right to data portability:* the beneficiaries have the right to ask to provides copied about their data in structured, commonly used and readable format.

### **VI. Data Processing**

#### **CONFIDENTIALITY OF PERSONAL DATA**

Personal data is by definition classified as confidential. The confidentiality of personal data must be respected by CUAMM personnel when processing personal data at all times.

In order to ensure and respect confidentiality, personal data must be filed and stored in a way that it is accessible only to authorized personnel and transferred only through the use of protected means of communication.

#### **SECURITY OF PERSONAL DATA**

CUAMM needs to ensure and implement a high level of data security that is appropriate to the risks presented by the nature and processing of personal data, the availability and quality of the necessary equipment, the cost and the operational feasibility.

CUAMM's data security measures are to protect personal data against the risk of accidental or unlawful/illegitimate destruction, loss, alteration, unauthorized disclosure of, or access to, personal data.

Having regard to the available technology and the cost of implementation, CUAMM needs to implement appropriate organizational and technical measures to ensure that the processing meets the requirements of this Policy. This includes the implementation of data protection enhancing technologies and tools to enable data processors to better protect personal data.

Organizational measures include:

- (i) Organizing staff training in data protection and security; and
- (ii) Conducting data protection impact assessments (Part 4.5).

Technical measures include:

- (i) Maintaining physical security of premises, portable equipment, individual case files and records;
- (ii) Maintaining computer and information technology (IT) security, for example, access control (e.g. passwords, tiered access), user control, storage control, input control, communication and transport control (e.g., encryption).

**VII. Data used in Research (including Data Sharing and Secondary Use of Data)**

CUAMM is committed to carrying out operational research in an open, transparent and accountable manner and in accordance with the principles of all applicable medical confidentiality, privacy, health ethics and health research laws, and in line with the research law of the Country of application, regulations and good practices.

This includes the 'do no harm' principle, respecting beneficiaries' autonomy, confidentiality, the beneficiaries' right to informed consent and the fair and equitable sharing of benefits.

CUAMM shall carefully and systematically assess issues of potential harm from use of data in research and shall seek ethical clearance from national ethics committees as appropriate.

The aim of using beneficiary's data in research is to bring wider health benefits to the individuals and communities where CUAMM operates.

CUAMM does not use patient data for commercial purposes and will use its best efforts to ensure that all results of research are widely disseminated, in a timely manner and do not lead to prohibitively costly approaches, restrictive intellectual property strategies or any other issues that may inhibit or delay the use of the results to the benefit of the communities.

In addition to respecting all applicable medical confidentiality, privacy, health ethics and health research laws, regulations and good practices (which set additional requirements to this policy on the use of peoples' data in research), for research involving identifiable data:

CUAMM shall carry out prospective research with patient informed consent and CUAMM shall systematically seek consent for secondary use of de-identified data. If beneficiaries "opt out" of secondary use of their de-identified data, then no further use of it shall be made.

CUAMM can use the data from projects or already existing data-sets for scientific or historical research: All data from projects will be used for research purpose only after the written approval of the owner of the data. Like prospective research, retrospective research is also subject to ethics review. CUAMM shall perform retrospective research (itself or with others) only when:

- the use for research is proportionate to the aim pursued;
- adequate technical and organizational safeguards have been put in place to make sure the minimum amount of data necessary is used/transferred;
- where informed consent for using data in research was not obtained, an approach to consent and/or waiver of consent is approved by or in accordance with the rules of the responsible ethics committee of the country of the beneficiaries;
- all other applicable ethical and legal research rules are respected.

#### **VIII. Sharing data with third parties for research**

For research purpose CUAMM can share anonymized data for which the permission to be used for research has been obtained to research partners officially involved in the study. CUAMM recognizes the ethical imperative it has to share de-identified data openly, transparently and in a timely manner with the appropriate safeguards to support or create evidence for the greater public health good, which needs to rely on good practices in data collection, use and management. As permitted by ethical and legal rules, under certain conditions, CUAMM may use or share anonymized, de-identified and/or aggregated health information for statistical, historical or scientific purposes, according to the research conditions set out above, the rest of the terms of this Policy.

#### **IX. International Data Transfers**

Where permitted by ethical and legal standards, under certain conditions, CUAMM may decide, for statistical, historical or scientific purposes, subject to the research conditions, to transfer personal data out of the European Economic Area (EEA). In this case, the responsible person must ensure that adequate safeguards are in place and the transfer shall not be initiated without the prior consultation of the responsible of CARRARO Dante.

In addition, CUAMM is committed to ensuring a minimum standard of data protection and confidentiality to protect the beneficiaries and the organization itself. Moreover, the beneficiaries will be informed of the transfer of its data to another country, beneficiaries that could accept or not to share its data in accordance with this policy.

#### **X. Personal Data Breach**

The organization does not tolerate any violation of the data of its beneficiaries, for this reason, when staff members, or other persons are suspected of any possible Personal Data Breach, it must be reported to [privacy@cuamm.org](mailto:privacy@cuamm.org) immediately. The organization will seek to carry out incident management and take appropriate corrective action in a timely manner, respecting the rights of beneficiaries and informing the competent authorities.

**Related documents**

- Child Safeguarding Policy
- Code of Conduct
- PSEA Policy and Whistleblowing
- Antifraud Policy