

INFORMATION SHEET ON PERSONAL DATA PROCESSING AND PROTECTION

Reference: ICMP Policy on Personal Data Processing and Protection (ICMP.POL.DG.04.doc)

WHAT IS PERSONAL DATA?

Personal data is any information relating to an individual human being. This may include a person's name, date and country of birth, and gender. Sensitive personal data refers to personal data that indicates race, ethnic origin, religious, philosophical, or political association, or other potential grounds for discrimination.

Sensitive personal data also includes biological samples of an individual or their relatives and the data derived from these samples. A biological sample is a sample of biological material that contains the genetic make-up of a person, i.e. his or her DNA. DNA is made up of many genes. Every person's DNA is unique. Genetic testing can be performed for multiple reasons, including research, the diagnosis of medical conditions, or to compare DNA from different individuals in order to detect family relationships. Genetic testing can be used to obtain reliable information on the fate and whereabouts of a missing person.

WHY DOES THE INTERNATIONAL COMMISSION ON MISSING PERSONS (ICMP) ASK FAMILY MEMBERS TO PROVIDE PERSONAL DATA?

ICMP assists domestic authorities and others in their efforts to account for missing persons. Basic information about a missing person – name, physical description and time and location of disappearance – may help to locate that person. ICMP also uses DNA to identify mortal remains of missing persons, and collects contact details of family members of the missing in order to request DNA reference samples. DNA can also be used to link living persons, such as children, to their families. ICMP asks family members to provide their blood DNA reference samples because they may be the next of kin to a person who has been reported missing.

HOW IS PERSONAL DATA OBTAINED AND KEPT?

ICMP has developed the **Identification Data Management System (iDMS)**, specialized software that makes it possible to store, view, analyze and share very large amounts of data on missing persons, investigations, and scientific identifications of the missing. The iDMS enables the efficient management of large amounts of data relevant to missing persons and includes a registry of missing persons and associated information, as well as information on DNA samples obtained from families of the missing, and the ability to conduct DNA matching between family members.

ICMP has also developed an online platform for the iDMS, called the **Online Inquiry Center (OIC)**. The OIC is an interactive missing persons search tool. It has an open-access function that allows families and other stakeholders to obtain and provide information. When reporting a missing person, family members are asked to provide basic information about the missing person, such as name and physical description, as well as the circumstances of disappearance.

When reporting a missing person, family members are asked to provide their consent for the use of the information they provide, including their personal data, for the purpose of accounting for missing persons and additionally, if they so wish, for the purpose of assisting justice processes. A family member may report more than one missing person. The consent constitutes a legal basis for ICMP to process the personal data they have provided for the specific purposes that have been stated.

WHAT IS DATA PROTECTION?

Data protection is the systematic application of a set of institutional, technical and physical safeguards that preserve the right to privacy with respect to the collection, storage, use and disclosure of personal data, i.e. the processing of personal data. When processing and sharing personal data the welfare of the individual takes priority over the rights and interest of society. To guard against the various risks associated with personal data processing – such as accidental loss of data, theft, manipulation or other forms of unauthorized processing – ICMP has adopted data protection measures that enable broad and secure participation in programs by families, their associations and others.

WHAT MEASURES DOES ICMP TAKE TO PROTECT PERSONAL DATA?

The iDMS and OIC in particular have been designed to ensure a high degree of control over access to sensitive information, such as DNA profiles and family data. ICMP has adopted technical, organizational, and legal security measures to protect personal data:

- The data systems are protected against cyberattacks, are regularly reviewed for their safety and are hosted only on ICMP's own IT servers;
- Users are authorized and have access to databases only on a "need to see" basis;
- DNA profiles are processed in an anonymous, coded form;
- As a treaty-based intergovernmental organization, ICMP benefits from privileges and immunities that guarantee legal protections of data, and the database and data processing systems.

CRIMINAL TRIALS AND CIVIL SUITS

Personal data can play an important role in criminal justice processes related to war crimes, crimes against humanity, and genocide. Criminal justice institutions may ask ICMP for assistance with investigations, or to testify in trials. ICMP ensures the protection of personal data and does not provide, for use in criminal prosecutions, personal information entrusted to it by family members of missing persons without their consent. Genetic data can also play an important role in civil lawsuits, including lawsuits involving paternity questions. As a rule, ICMP will not facilitate civil lawsuits that are subject to national laws and procedures.

ACCESS BY FAMILY MEMBERS TO THEIR GENETIC DATA

Family members are asked to release ICMP from any obligation to provide them or any other party with the results of genetic analysis performed by ICMP. Should the family members wish to obtain their own sensitive personal data, including their genetic profile or other genetic information, they should do so subject to rules governing genetic testing in their country.

THE RIGHT OF FAMILY MEMBERS TO WITHDRAW CONSENT

Family members have the right to withdraw consent at any time. ICMP will discard personal information in an appropriate and timely manner. Family members also have the right to amend or correct their personal data. In the event that genetic and other personal data form part of official conclusions in a given case, such as in the identification of the mortal remains of a missing person, then that data can no longer be withdrawn.

FURTHER QUESTIONS

For further information about data processing and protection, please contact ICMP at icmp@icmp.int or visit the ICMP website at www.icmp.int.