



Guide to the **Collection, Protection, Processing and Sharing of Data** to Support Investigation and Identification of Missing Persons



The International Commission on Missing Persons (ICMP) has produced this Guide for families of the missing and civil society organizations (CSOs) in Ukraine to show how they can cooperate with ICMP and with the national institutions of Ukraine to account for those who have gone missing as a result of the Russian invasion. The Guide explains how ICMP collects, protects, and uses data to facilitate identifications, and how it shares data with Ukrainian institutions that are responsible for accounting for missing persons.

Q: What is personal data?

A: Personal data is any information about an individual human being. This may include a person's name, date of birth, place 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. Genetic data – an individual's DNA – always constitutes sensitive personal data.

Q: Why does ICMP ask family members to provide personal data?

A: ICMP asks family members of missing persons to provide personal data, including DNA, to help government institutions and other authorities account for missing persons. DNA may be necessary to identify human remains. DNA can also be used to reunite separated children with their families.

Q: What does ICMP do with personal data?

A: ICMP combines data provided by **relatives** with data obtained from **other sources**. ICMP collects **blood or saliva** from family members and extracts DNA. Using a mass database, this DNA is compared with DNA extracted from unidentified human remains. A DNA match exceeds a very high statistical certainty of identity – at least **99.95 percent**. When there is a DNA match, ICMP submits a **DNA Match Report** to the authorities so that an official identification can be made. ICMP may receive and process post-mortem samples from unidentified human remains on the basis of court orders or orders from investigators and prosecutors. ICMP conducts DNA testing at no financial cost to the families of the missing.

Q: Which family member's data is useful?

A: Family members share **similar and predictable patterns** in their DNA profiles. The DNA profiles of close family members, such as parents, children and siblings, are the most useful. Usually, DNA from **more than one** close relative is needed. The DNA profiles of spouses can also be used if the children of the spouse and the missing person are available to provide reference samples. The DNA profiles of more distant relatives (uncles, aunts, cousins) can also be useful, particularly if profiles from multiple relatives can be collected, or if such profiles are used in combination with the profile of one or more close relatives.



Q: Can ICMP receive data from families of the missing?

A: Families of missing persons have **the right to provide** their personal information to others. They are free to seek, receive and impart information, including across borders, and they have **the right to access and communicate** with international agencies. The right to seek and share information includes reporting a missing relative and sharing necessary personal information to facilitate locating the missing relative. ICMP is focusing on the collection of data from families of missing persons from Ukraine who are currently refugees in European states, in support of the identification effort in Ukraine.

Q: Do family members control their data?

A: Family members have **the right to withdraw, amend or correct their personal data**. However, in the event that genetic and other personal data form part of official conclusions, such as in a family reunification or the identification of human remains, this data can no longer be withdrawn. ICMP transmits personal data of family members to other organizations or institutions only with the free, informed and express consent of family members who are capable of expressing such consent.

Q: How does ICMP cooperate with the National Police of Ukraine?

A: ICMP cooperates with the National Police of Ukraine (NPU) on the basis of a Protocol signed by ICMP and the NPU on 30 August 2023, the International Day of the Disappeared. ICMP is supporting the NPU by **sharing data**, including DNA profiles, provided by people who have reported missing

relatives to ICMP and who have provided written consent to ICMP to share their data with the NPU. DNA profiles of family members remain in ICMP's database after being submitted to the NPU. **ICMP does not share biological samples provided by relatives with the NPU.**

ICMP provides to family members the NPU's Information Sheet on Data Processing and Protection, together with ICMP's information sheet, when collecting data from families of the missing.

Q: How does the NPU protect data?

- A:**
- NPU will always treat the genetic and other personal data of family members as **confidential**.
 - NPU processes DNA profiles provided by relatives **only for the purposes of locating and identifying missing persons**, unless relatives provide express consent that their data may also be used for purposes of criminal investigation and trials.
 - NPU holds DNA profiles provided by family members **separately from any criminal data or databases used in criminal investigations**, and no comparison to such data will be done for purposes of identifying, by means of the data, possible perpetrators of criminal activities.
 - NPU may transmit data provided by family members, including genetic data, to **public or private services** that support NPU's missing persons work.
 - At no time will NPU process or transmit more personal data than is necessary to achieve the purposes for which family members have given consent or allow persons to access the data for such other purposes. Genetic data will be processed in an **anonymous alphanumerical format whenever possible**.
 - The processing of DNA data is carried out via **secure communications channels** and in **compliance with the laws of Ukraine**.



Q: How does the NPU safeguard the rights of families?

- A:**
- NPU safeguards **family members' privacy rights**, including their rights to lawful, fair and transparent processing of their data, as well as the right to withdraw, amend or correct personal data.
 - Withdrawing consent means that a family member informs NPU that NPU shall **stop processing personal data** the family member has previously submitted. In that event NPU will delete the data for any future use.
 - NPU will **not retain** family data for longer than necessary to achieve the purposes for which it was provided.

Q: Who notifies the families when a positive DNA match is found and a DNA Match Report is issued?

- A:** The Ukrainian authorities are **responsible** for notifying families that their DNA profiles match the DNA taken from a set of human remains. When a DNA match is found that exceeds the **99.95 percent threshold**, ICMP submits a DNA Match Report to the investigator, prosecutor or pathologist who ordered the post-mortem sample to be sent to ICMP for DNA testing.

Q: As a family member, how do I find out if ICMP has submitted a DNA Match Report to the Ukrainian authorities?

A: Family members can check if ICMP has submitted a DNA Match Report to the Ukrainian authorities by entering the name and surname of their missing relative in the **Missing Persons Inquiry application in ICMP's Online Inquiry Center**. If a report has been submitted, the family member will see a notification showing the date on which the information was passed to the relevant authority.

Q: Does ICMP provide copies of DNA Match Reports to families of missing persons when a DNA match is found?

A: ICMP only provides the DNA Match Report to **competent authorities** investigating missing persons cases.

Q: Does ICMP deploy investigative teams?

A: ICMP, upon a request from an investigator or prosecutor, may provide **forensic experts** to assist the authorities with all aspects of investigations.

ABOUT ICMP

ICMP is a treaty-based intergovernmental organization. It seeks to secure the cooperation of governments and other authorities in locating and identifying persons missing as a result of conflicts, human rights abuses, disasters, organized violence, irregular migration and other causes and to assist them in doing so. ICMP also supports the work of other organizations in their efforts, encourages public involvement in its activities and contributes to the development of appropriate expressions of commemoration and tribute to the missing.

ICMP was created at the 1996 G-7 Summit in Lyon to address the issue of persons missing as a consequence of the conflicts in the Western Balkans. Starting in 2004, it began working globally. In 2014, the Netherlands, the United Kingdom, Belgium, Sweden and Luxembourg signed an international agreement establishing ICMP as an intergovernmental organization with Headquarters in The Hague to respond to the global challenge of missing persons.

ICMP has been assisting the authorities in Ukraine since 2014. Immediately after the 2022 invasion, the authorities in Kyiv asked ICMP to expand its activities.

ICMP's current Ukraine Program, launched in late 2022, is supported by the Government of Canada, the European Union Service for Foreign Policy Instruments (FPI), the US State Department Bureau of Democracy, Human Rights, and Labor (DRL), and the German Federal Foreign Office.



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