

Data in the Fight against Impunity Capturing torture survivors' information about torture, impunity and rehabilitation



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OVERVIEW REPORT 2017

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The International Rehabilitation Council for Torture Victims (IRCT) is an independent, international health-based human rights organisation which promotes and supports the rehabilitation of torture victims, promotes access to justice and works for the prevention of torture worldwide.

The vision of the IRCT is a world without torture.

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against Impunity (DFI) Project.



The work of the IRCT

As a network of some 150 torture rehabilitation centres in more than 70 countries, the IRCT is the world's largest membership-based civil society organisation working in the field of torture rehabilitation and prevention. Its key distinctive feature lies in a holistic health-based approach to torture rehabilitation. In addition, the organisation defines itself as private, non-partisan and not-for-profit, as well as being governed by democratic structures.

The IRCT's diverse membership shares three common characteristics: **each member is a legally independent organisation that is rooted in civil society; each provides services to at least 50 torture victims annually; and each is committed to sharing its experiences throughout the IRCT and beyond.** IRCT member centres stem from all regions of the world. Given the very nature of the organisation, some of these centres may be newly established, small or fragile from an organisational perspective, while others have long trajectories of public service, appropriate budgets and solid funding structures. Together the movement is effective in fighting torture across the globe. The core strength of the movement stems from a triad of values: Solidarity, Equality and Democracy.

IRCT's network:

151

organizations

73

countries

Project partners & centres

| DFI Project Partners | Country | DFI Implementing Centres (Phase 2) | Country |
|----------------------|----------------------------------|------------------------------------|--------------|
| EATIP | Argentina | ARCT | Albania |
| CTV | Bosnia & Herzegovina | FAVL | Armenia |
| TCC | Cameroon | CRTS | Bangladesh |
| AJPNV | Chad | ITEI | Bolivia |
| MATESO | Kenya | SAVE CONGO | DRC |
| CCTI | Mexico | RCT/EMPATHY | Georgia |
| TPO Nepal | Nepal | CPTRT | Honduras |
| TRC Palestine | Occupied Palestinian Territories | CORE - H2H | India |
| MAG | Philippines | SOSRAC | India |
| BALAY | Philippines | CLDH-Centre Nassim | Lebanon |
| IAN | Serbia | CAT | Kenya |
| RCT Zagreb | Croatia (Associate Partner) | KHIAM | Lebanon |
| | | RCTV MEMORIA | Moldova |
| | | PRAWA | Nigeria |
| | | CPT | Russia |
| | | CAPREC | Senegal |
| | | TCSVT | South Africa |
| | | SURASO | Sri Lanka |
| | | FRCSL | Sri Lanka |
| | | HRFT | Turkey |
| | | ACTV | Uganda |

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For further information on the DFI project and on further steps to build clinical information as a resource please contact www.irct.org or Leanne MacMillan, Director, Research and Development: lm@irct.org or Lisa Haagensen, Project Coordinator: lh@irct.org

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Sponsors of the DFI Project include generous funding from the European Union and additional support from the governments of Denmark, Norway, Sweden, the Lauritzen Fonden and the OAK Foundation.

Cover Photograph

DFI meeting. Pictured from left to right: Edith Escareno Granados (CCTI Mexico); Andres Gautier (ITEI Bolivia); Víctor Morales Rodas (CPTRT Honduras); Laure Gattinoni (EATIP Argentina).

“I see this data as a very important record of humanity, something like monuments and memorial objects. It takes decades for people to acknowledge officially that people were victims... I believe that this database should not be considered as just a medical record or records that we keep as (torture rehabilitation) service providers, but as a history of what we are capable of, but also of how we recover as human beings.”

Hyuni Ahn
KMHC South Korea

BACKGROUND

— Unique Capacity of the Torture Rehabilitation Movement to Harness Evidence of Torture

The Data in the Fight against Impunity (DFI) project, which started in 2014 and ended in mid-2017, has become central to the development of the torture rehabilitation sector's ability to evidence its work in the fight against impunity. It does so through the collection of appropriate, consistent and comparable information that is provided by torture victims to their care providers in the setting of a holistic torture rehabilitation service. Over the course of 3 years, the project partners from around the globe, carefully laid the foundation to evidence claims for the rehabilitation of torture survivors, to prevent torture and hold perpetrators to account.

This project recognizes the unique capacity of torture rehabilitation service providers to support survivors and while doing so to access the vital information that survivors hold. It affirms the complementarity of the provision of a clinical service with the imperative of seeking justice. The DFI database optimizes documentation that can be used in pursuit of human rights outcomes.

The creation of a common clinical record keeping system for torture rehabilitation service providers to use in their daily practice was a significant challenge considering the wide range of practice environments and resources of those providing torture rehabilitation services and support. But it is a challenge that the project partners took up, and over 3 years they did the painstaking work of defining the content and structure of the system.

The DFI database has been widely acknowledged as a unique and innovative approach to harnessing the information that torture victims can provide to track torture, but also to examine a survivor's rehabilitation needs and path. Most importantly, by establishing a common and shared basis of information collected by individual service providers at torture rehabilitation centres around the world, the opportunity for increasing our evidence base is secured. As the number of individual records increases, so too does the capacity for local to global advocacy efforts.

This project recognizes the unique capacity of torture rehabilitation service providers to support survivors and while doing so to access the vital information that survivors hold.

The DFI database is also unique because it addresses the challenge of disclosure. It is well established that victims of torture do not disclose their torture immediately. Some may not reveal that they have been tortured for many years. This can be for a myriad of reasons ranging from a lack of trust, fear that there will be repercussions, stigma or further risk of harm, or an inability to recall details of their torture and of the perpetrator.

At the heart of this project was an understanding of the challenge of disclosure and a clear desire to ensure that no matter when and to whom a survivor disclosed information about their torture, that this vital information would be recorded in a coherent and secure way. This information would stand as a record over time that could be used for a host of human rights and rehabilitation purposes.

This report sets out how the DFI project built a systematic way to secure, safely store and share data and information across rehabilitation service and country contexts. It describes how the database was built through participation, consultation and testing through pilots. It shows how it has emboldened the ability of the IRCT member centres to use data to support their advocacy and communications about who is being tortured, who tortures them and to fight impunity. Finally, it takes a glimpse into the future of the database as a sustainable part of the overall effort to collect and use clinical records in pursuit of all the human rights relevant to torture victims.

IRCT Member Centre and Project Partner
MATESO, Kenya.



Objectives of the DFI database project

The objectives for this project were framed on an understanding that at the heart of fighting impunity for torture is the accurate collation of information and evidence. The specific objective of the project was to strengthen and harmonize the capacity of rehabilitation centres to collect clinical data and use it to produce human rights outputs to support anti-impunity work.

With its global network, IRCT membership was seen as uniquely positioned to support torture survivors to provide information about their torture that could be used to increase accountability among governments. At its most basic level the project aimed to build capacity of torture rehabilitation centres to improve the collation and dissemination of clinical data on torture, thereby supporting the rehabilitation of torture survivors, whilst contributing to a better understanding of the causal factors of torture and the evidence base to be used against torture perpetrators. Broadly, over the course of three years the project aimed to:

Strengthen the capacity and network of up to 35 torture rehabilitation centres located across 5 regions and to make the database available to the wider global community providing services in at least 50 countries.

Create standardised evidence collation methods to accurately document instances of torture and strengthen the evidence base against torture perpetrators.

Provide support for survivors in their rehabilitation and participation in torture prevention measures by sharing their stories and information.

Analyse trends and patterns of torture to develop a detailed understanding of the causal factors of torture and to use these in advocacy and communication efforts from the local to global level.

The Journey to Build the DFI Database

Central to the development of the sector's ability to evidence its work, is the collection of appropriate, consistent and comparable clinical information. The DFI Project represents a system-wide response to this need.

The DFI database project was structured in 3 major phases. It was based on an ethos of grounding our work at the local level, participation and building a network that could ensure sustainability of the project.

In Phase 1, the IRCT member centres piloting the project were selected on the basis of regional balance and capacity to represent the full range of rehabilitation practices across the movement. They also needed to provide leadership in each stage of the project and commit to be part of a longstanding program of work.

As part of this first phase of the project, a baseline survey was carried out to establish the capacities and developmental needs of the partners. This survey, along with an intensive 5 day planning meeting, served as the basis for determining the structure and content of the first version of the database. Partners chose the most appropriate data system given their collective contexts and agreed on a detailed set of data elements and reporting structure; identified themes for research and advocacy and communications outputs and developed criteria for adding other rehabilitation centres to widen the scope of data collection. They also laid the foundation for establishing a network of partners and shared experiences on how to strategically use clinical data for human rights outputs, communications and advocacy.

Over the course of many months of dialogue, piloting and modifications based on practical experience with the database, the project launched phase 2. This second phase also benefitted from an extensive external evaluation that served to support the unique nature of the project and addressed the challenges of increasing the number of individual victim clinical records at a pace needed to support advocacy efforts. It underscored emphatically the need for the database.

At the beginning of phase 2 there was a global call for additional partners in the project who would benefit from using the database developed in phase 1 and contribute to its future sustainability. Criteria were applied to ensure a representative and geographically balanced number of torture rehabilitation centres that qualified under the EU project criteria for grant recipients. Based on this a further 21 centres joined the project.

Through a series of intensive regional training workshops (in Asia, Europe, MENA and Sub Saharan Africa) representatives from these centres were trained on the database and on how to use data strategically through advocacy and communications approaches in the fight against impunity.

Central to the development of the sector's ability to evidence its work, is the collection of appropriate, consistent and comparable clinical information. The DFI Project represents a system-wide response to this need.

DFI Database Interface

This is the home page of the current DFI database, designed to be user friendly across all rehabilitation service providers:

The screenshot displays the DFI Database Interface dashboard. At the top, it shows 'Version 1.1' and 'Release Date : 11-11-2016 22:49 GMT'. There are buttons for 'Refresh', 'Change Password', and 'Logout'. The 'Statistical Summary' section contains five cards: 'New Clients' (4 Case(s)), 'Ongoing' (7 Case(s)), 'Inactive Clients' (0 Case(s)), 'Readmission' (0 Case(s)), and 'Total' (11 Case(s)). Below this is the 'Dashboard Menu Links' section with eight buttons: 'New Client' (Click here to register a client), 'List of Clients' (Click here to view the list of clients), 'Reports' (Click here to view reports), 'System Users' (Click here to register and manage system users), 'Settings' (Click here to access system settings), 'User Manual' (Click here to learn how to use the system), 'Backup Restore' (Click here to backup data), and 'System Log' (Click to view system log). The bottom right corner features the European Union flag and the 'irct' logo. The Windows taskbar at the bottom shows the time as 10:01 on 12-11-2016.

At the end of phase 2, a standardised clinical record-keeping system was in place in 33 member centres in 28 countries. Throughout this phase, improvements were made to the database structure, it was translated into 5 languages, a data dictionary and other training tools were developed to ensure that the database was being used properly and that the data was of high quality and consistent across contexts. Modifications for the next version of the database were started during this phase to meet security, data integrity and user-experience concerns.

It was also during this phase that efforts continued to communicate the data generated by partners. Dozens of individual client narratives were shared in an effort to communicate widely the human face of torture. Survivor stories form an important aspect of building an understanding of who is tortured, the effect it has on them, their families and communities and to show who perpetrates torture and needs to be held to account. These stories formed the basis for a number of IRCT external communications.

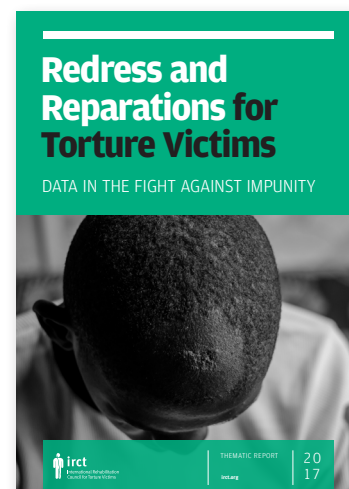
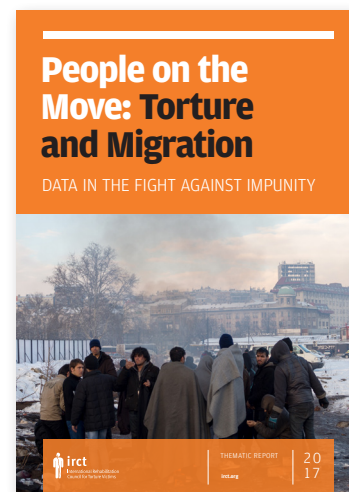
In the interest of sharing data across borders for advocacy purposes, the project partners agreed on producing thematic reports on issues that were of keen interest to all of them. They produced thematic reports on sexual torture, redress and reparations and migration. This level of collaboration of torture rehabilitation centres was unprecedented and provided an early sign of the potential and power of sharing information and data across contexts and countries.

While there were many challenges in securing enough data at this stage - due to the brief time there was to amass client records - several reports were generated from the DFI data that were used for reports filed with UN treaty bodies and thematic mechanisms. Centres also harnessed DFI data to support the national strategic plans they had developed which included providing evidence to governments on the need to end impunity. Some DFI partners used DFI data to advocate that the Committee Against Torture and Universal Periodic Review issue recommendations aligned with their respective national priorities. DFI partners from Palestine, the Philippines and Uganda also prepared reports. With the support of IRCT Secretariat experts in advocacy, these reports were a significant contribution to the advocacy efforts torture rehabilitation centres made at the national level by bringing their country to the attention of global bodies.

It was also during this phase of the project that the DFI database was gaining increasing interest of other human rights and clinical services organisations keen to have access to the database. They reviewed the database, borrowed its innovations and suggested how to improve it with a view to expanding its use beyond the countries within the remit of the EU for funding in the project. It was also presented to the UN Committee against Torture, to representatives of the UN Sub-Committee for the Prevention of Torture, the UN Voluntary Fund for Victims of Torture and other global human rights NGOs. At the 10th IRCT Scientific Symposium held in Mexico in late 2016, over a hundred Symposium participants viewed it.

In the final and third phase of the project, the focus was on sharing the database directly with all members of the IRCT global movement through intensive regional workshops. At this stage, the database was meeting many of the needs

Thematic Reports



of the current users and the phase 3 regional workshops provided an opportunity to make final modifications with the benefit of all IRCT member centres in attendance. These workshops proved of immense value in taking stock of how to perfect the database and to ensure its sustainability.

A number of issues that are of continuing interest were addressed and these are discussed in detail below in relation to how to take this database forward. In sum, there was a keen emphasis on security, responsible data management and ethics, data sharing and use agreements, the use of clinical information for documentation, advocacy and research purposes and the related rights of survivors and the duties of individual care providers and clinical services.

It was not unlikely that in this final phase of the project when widening the scope of application, that there is a continuing interest in improvements to secure, stabilize and sustain the DFI database. It should also be noted however, that many of these issues are not new to organisations providing clinical services and keeping client records. The DFI project created the context for a number of practice related concerns to surface including:

Agreement on definitions such as how to classify types of torture; types of perpetrators; the difference between primary and secondary victims;

Agreement on which clinical diagnostic tools to use;

Practice issues such as how to encourage compliance in filling out the database and keeping it current; resource challenges and how to respond to high staff turnover; how to prioritise funding this area of work and its connection to monitoring and evaluation;

Security of victims, care providers, data and the system in light of the detailed information held;

Data use and sharing agreements that would ensure ethical and legal requirements were respected in relation to informed consent, the collecting, storing, sharing and any transfer of this type of information.

In this final phase there was an effort to determine where centre interests were in further uses of the database. Four pillars were identified for a stocktaking exercise on using the DFI database.

1, as a clinical record keeping system for practice management and sustainability; 2, as the basis for anti-impunity and torture prevention work; 3, to evidence the right to rehabilitation; and 4, for documentation, research and networking more broadly.

There was a fairly even distribution of centres under each pillar, and most significantly, a number of IRCT members who want immediate access to the database to start using it at their centres. There were also distinct regional variances.

A number of IRCT members who participated in the final workshops are part of well-established networks in the United States, The National Consortium of Torture and Trauma Programs (NCTTP), and in Australia, Forum of Rehabilitation Services for Survivors of Torture and Trauma (FASSTT). They hold significant data and represent a large number of rehabilitation centres. There was an interest in creating the conditions necessary to align and share the information and data already held to optimize our shared work in torture prevention, anti-impunity and rehabilitation of survivors.

Four pillars for use of the DFI database

- 1 As a clinical record keeping system for practice management and sustainability
- 2 As the basis for anti-impunity and torture prevention work
- 3 To evidence the right to rehabilitation
- 4 For documentation, research and networking more broadly



DFI meeting for the Europe region in Belgrade, Serbia.

Anticlockwise from right:

Bojana Trivuncic (IAN Serbia), Bianca Schmolze (MFH Bochum Germany), Lela Tsiskarishvili (GCRT Georgia), Mechtild Wenk-Ansohn (Zentrum Überleben Germany), Annette Carnemalm, Elisabeth Bakke (Red Cross Centre Stockholm Sweden) and Carrie Gaston (FFT United Kingdom).

“For me, the DFI meeting was extremely insightful for understanding how we, as a movement, can make a difference on a macro level. If we organize ourselves, come to a consensus on collection of similar sets of data we can make a difference beyond our individual centres and clients. I do believe that by collecting data in a uniform way - evidencing patterns of torture, identifying the perpetrators, understanding who are the most vulnerable groups that are submitted to the acts of torture, seeing the sequelae, etc. will give us a louder voice - and envisage that the DFI is a platform for reaching this overarching goal.”

Lela Tsiskarishvili

Executive Director, The Georgian Center for Psychosocial and Medical Rehabilitation for Torture Victims - GCRT and member for Europe of the IRCT Executive Committee

FOUNDATION FOR THE FUTURE

A Platform for Sustainability

Over the course of three years, the partners in the project built a standardized clinical record-keeping system that is currently being used in 33 member centres in 28 countries, with many waiting for the final version of the database so that they can use it. Other member centres in the IRCT membership, while not needing the DFI database itself, are very keen to identify and share common data sets and to correlate this data to widen the basis of evidence.

The IRCT member centres developing and piloting the project were selected on the basis of regional balance and capacity to represent the full range of rehabilitation practices across the movement. This was a strategic decision that has been borne out given the broad appeal of the database. At the end of the project it became clear that they had indeed built a firm foundation and are set to provide continuing leadership in any expansion of the DFI database and more generally, as part of the overall torture rehabilitation sector system-wide response to using clinical records to make human rights gains.

The challenge now is to take this project to a sustainable, longstanding program of work. There were some practical insights gained at the final round of workshops with IRCT members from over 60 countries.

Basic suggestions for additional content, how to make it more user friendly and to improve its security were either part of the most recent modification or are slated for the next version of the database in early 2018.

However, while these suggestions were important, three broad areas emerged. These are: ensuring the sustainability of the database; building a network of users who could reliably share data trusting each others data management practices and data quality; and building a minimum common data set that would allow for documentation and research for a range of purposes from human rights advocacy to evidencing best clinical practice.

The discussion at the workshops resulted in the following observations.

The challenge now is to take this project to a sustainable, longstanding program of work.

Ensuring sustainability:

Generally, centres were concerned to build competencies in interpretation and analysis of data for advocacy purposes; with how to harmonize and adapt the DFI database to local contexts which may include a wider practice base than torture survivors; with addressing staff not accustomed to or resisting using electronic record keeping systems; and with securing management support to provide resources to build greater capacity to use a database that would include such detailed information as under DFI. Of overall concern was the lack of compliance of all staff in appropriate record keeping. This was seen as a challenge going to the heart of clinical practice in across contexts where service demands are already overwhelming staff.

Centres agreed that they would need to develop internal policies for strengthening capacities of those using and managing the database through consistent training of staff, dedicated human resources and fostering an understanding of the importance of clinical record keeping in interdisciplinary, holistic team settings. There was also a concern to ensure funding for this area of work that would enable sustainability and emphasising that record keeping and data management in a clinical setting are a core part of a clinical practice. Many of the centres saw that the use of the DFI database had improved their fundraising horizons, as they were able to demonstrate clearly their client base and how they were able to support torture victims.

Risk management and security of the data, the database and responsible data management practices were seen as key to the sustainability of the database at each individual rehabilitation centre and also as integral to the overall sustainability of developing a common dataset and any joint data sharing and use as part of the DFI network.

Building a network of centres able to reliably share high quality data:

In order to have secure, reliable data it was understood that in addition to a high quality database there needed to be robust practices and an approach to share data across centres and contexts. The discussion in the workshops was consistent across all regions and focussed on developing standards for data quality and management. Most importantly, it was agreed that there be a shared understanding of the ethics of clinical record keeping, client

“The DFI database has strengthened the administrative and management systems that has ensured that we meet the minimum standards for funding by the UNVFVT and other donors”.

Abubakar Juma,
Director, CAT, Kenya

Top photo

Sub-Saharan Africa members reviewing the database at a regional workshop.

Bottom photo

DFI meeting for the North America and Pacific regions. From left: Crys Riley (TTCO USA) and Jose Quiroga (National Consortium of Torture and Trauma Programs, USA).



confidentiality, use of client data for advocacy and research, its storage and sharing.

Each workshop included a detailed discussion of the ethics and practice of informed consent. There was a detailed discussion about the duty of rehabilitation service providers to have a practice-led approach to informed consent, ensuring that a client is informed about what information is being collected, how it will be used, and their rights in relation to this data. This raised questions about the use of aggregated data and who in fact owns data once its been ‘processed’ so many times.

There was a keen discussion in the workshops on the need for understanding standards for the collection, use, security and retention of clinical records and any related legislative or professional standards for using this information for research purposes. It would be important to build a resource of this information as part of the knowledge retained by the network using DFI data to ensure compliance and most importantly, to respect the rights of survivors on any use of information.

It was clear that in furthering our work as a movement collecting and sharing data under the DFI or any other network, we would need to secure a data use agreement in accordance with each particular context and legal requirements. It is clear that there are a number of matters to clarify when sharing data of this nature, but it is also clear that there is much good practice, agreed procedures and understandings of duties in this regard. The overwhelming interest is to collaborate in the interest of compiling compelling information in the important human rights work to be done and this may mean reinforcing some practices at the individual practitioner and practice level.

Other practical ideas made at the regional workshops included developing a network of those in IRCT member centres with expertise in databases and data use; to create a research group to develop priorities for research questions that could be answered by sharing data; to establish a basis for communication and problem solving within the IRCT membership, and to make better use of the discussion forum on the IRCT Members Site. There was an interest in sharing knowledge and generally in engaging in peer support and other capacity building approaches.



DFI meeting.

Left to right: Wisam S. Abdallah (TRC Occupied Palestinian Territories); Lina El Dana (KHIAM Lebanon); Flutra Gorana (CLDH-Nassim Lebanon).

Building a minimum common data set:

There was a high degree of consensus on what might be a meaningful minimum common data set that could be of great use for both human rights purposes and speaking meaningfully to the right to rehabilitation. When comparing existing networks such as the longstanding USA based National Consortium of Torture Treatment Programs (NCTTP) and the DFI database, there are already close to 20 datasets that are of comparative value. The Forum of Rehabilitation Services for Survivors of Torture and Trauma (FASSTT) network in Australia is considering how to align some of its datasets to render them compatible with the DFI database. Some of the larger torture rehabilitation centres with significant data in an already robust database have been investigating the DFI database to see where there is a common basis for action.

Ways forward:

The workshops in 6 regions around the world emphatically affirmed the success of the database and the numerous advocacy outputs produced during the project period. It is the only global database of its kind and represents a strong foundation for the future. Working with the other regional networks to collect similar data will only embolden our global capacity.

The IRCT membership that coalesced around the DFI database project have identified a common purpose in pursuing the long path to justice by making best use of information we hold by aligning databases and datasets. They have also identified the need for resources and to improve some practices such as data use agreements and respect for victims' rights in relation to the information they share during the process of rehabilitation.

This affirms our unique position as torture rehabilitation service providers to secure high quality information, in an ethical and robust manner and to deploy it for a host of human rights purposes and to evidence the rehabilitation needs of torture victims.



Top:
Pitambar Koirala (TPO Nepal) and the DFI Team at TPO Nepal with IRCT Secretariat staff members.

Bottom:
Makwan Mohammed Abdulkareem (Jiyar Foundation for Human Rights Iraq).



The IRCT membership that coalesced around the DFI database project have identified a common purpose in pursuing the long path to justice by making best use of information we hold by aligning databases and datasets. They have also identified the need for resources and to improve some practices such as data use agreements and respect for victims' rights in relation to the information they share during the process of rehabilitation.

How to support the IRCT

We need your support to fight torture and to help torture survivors rebuild their lives. By donating even a small sum, you can assist us to put an end to torture and to ensure that torture survivors and their families receive much-needed treatment and other services

By credit card

Please visit www.irct.org to make a donation using a credit card. All transactions are guaranteed safe and secure using the latest encryption to protect your personal information.

By cheque

Cheques made payable to the International Rehabilitation Council for Torture Victims (IRCT) should be sent to:

International Rehabilitation Council for Torture Victims
Vesterbrogade 149, building 4, 3rd floor
1620 Copenhagen V, Denmark

By bank transfer

Danske Bank
Holmens Kanal Branch
Holmens Kanal 2
1090 Copenhagen K
Denmark
SWIFT code: DABADKKK

Danish Kroner (DKK) Account

Registration No. 4183
Account No. 4310-821152
IBAN DK90 3000 4310 8211 52

Euro (EUR) Account

Registration No. 4183
Account No. 3001-957171
IBAN DK69 3000 3001 9571 71

U.S. Dollars (USD) Account

Registration No. 4183
Account No. 4310-005029
IBAN DK18 3000 4310 0050 29





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