International Centre for
Health & Human Rights

Monitoring and Evaluation of Rehabilitation Services for Torture Survivors

Handbook for Service Providers

This handbook was written by Nimisha Patel and Amanda C de C Williams, International Centre for Health and Human Rights

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International Centre for Health and Human Rights
The International Centre for Health and Human Rights (ICHHR) is a UK registered charity (No. 1153689). We work to support the implementation of international human rights standards for health and rehabilitation of survivors of torture and other serious human rights violations. Our work includes conducting interdisciplinary research and harnessing available evidence, including practitioner-based evidence and survivors' experiences, to contribute to the development of practice and to inform policy related to the field.

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(http://www.ucl.ac.uk/psychlangsci/staff/cehp-staff/a_williams)

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1. Introduction

Torture survivors can be considered both the most vulnerable and resilient of people. They are a testimony to the human spirit and to the capacity for endurance in the face of unimaginable atrocities.

For three decades, the field of providing care and support, or 'rehabilitation', for torture survivors, has developed and flourished to encompass a wide range of interventions, prevention activities and advocacy , to address the needs of survivors and their families, whilst acknowledging their strengths and their survival. All these efforts, led by pioneers in the field, were developed in the absence of guidance on the best way to help torture survivors, and on the appropriate standards. These efforts were driven, and remain so, by a collective commitment and determination to stop torture, to help those whose lives had been shattered by torture, and to ensure that torture survivors are never again placed in danger and in the way of harm. At the heart of these efforts remains a profound urge by practitioners and service providers to respond to human suffering, and survival, in a way which is as humane and respectful as possible.

1.1 Background context

The guidance herein is aimed at service providers.

The context to these guidelines encompasses three key perspectives: those of service providers, donors, and academic/practitioner-researchers.

Service providers' perspectives

A large proportion of services for survivors of torture are offered outside mainstream, state healthcare provision. Globally, most services for torture survivors are provided by non-governmental organisations (NGOs). Services vary according to local needs, client population (e.g. refugees, asylum seekers, or 'in-country victims' of torture), and local political, social, economic and cultural contexts. Services are diverse, and multiple, offered either at the same time, or one after the other to torture survivors. Services are also tailored to each individual or family, according to their needs, resources, and situation. Many services are offered in a highly precarious environment where service providers, and torture survivors, are at risk of intimidation and harm. Service provision may include early intervention, crisis or long-term interventions, depending on needs of clients and on the local context.

Almost all service providers face a constant battle for survival, with limited resources and many demands. Staff members are often under immense pressure and strain from the work, feeling helpless and powerless at times, struggling to focus on their foremost concerns, the torture survivors they see, and to focus on their core and primary task – providing support and care to those torture survivors. Practitioners are also fully aware of limitations to any interventions or support they may offer in situations where their clients are living in threatening, insecure and dangerous environments.

Many services also engage in prevention activities, related to and as part of their rehabilitation strategies. This too creates additional demands on practitioners, though enhancing overall rehabilitation efforts. Service providers are only too aware of the need to monitor and evaluate direct client services alongside the full range of other services and activities they engage in

(e.g. advocacy, awareness-raising amongst health professionals, the public, other human rights activities, education, training and capacity-building of others), , since all contribute to rehabilitation.

Unfortunately, demands for monitoring and evaluation may be seen as an added burden to practitioners already weighed down by the sheer breadth, volume and enormity of their task. However committed to providing high quality services practitioners may be, the demands for monitoring and evaluation may pale into insignificance in terms of immediate priority in the face of the demands of a client who is on the verge of attempting suicide, or a client who is about to be returned to a place where they were tortured, or a family where there is violence towards the children and the mother by the parent who was tortured. Service providers will wish to do effective monitoring and evaluation, but daily demands and crises often hinder efforts to focus on what is essentially an institution-building and quality enhancement process. Compounding this is the lack of appropriately qualified and skilled staff to undertake the establishment, implementation and maintenance of monitoring and evaluation systems. The lack of dedicated resources to recruit appropriate staff and to develop the necessary institutional infrastructure is undoubtedly the single most important and enduring obstacle to effective monitoring and evaluation systems.

Donors' perspectives

It is clear that donors recognise and understand the difficulties service providers experience in their day-to-day work and the threats and pressures service providers face. Whilst many donors have steadfastly supported this field, funding for rehabilitation services for torture survivors is relatively limited and, service providers would argue, diminishing. At the same time, there is increasing pressure on states to ensure sustainable funding, as is their legal obligation, for rehabilitation services. In the current context, where advocacy efforts to ensure that states meet their obligation are mostly met with resounding silence, the pressure on rehabilitation services to simply survive to support torture survivors is greater than ever. Therefore, expectations that service providers will conduct monitoring and evaluation may be met with frustration, not because service providers do not want to do this but because the task is overwhelming and seen as requiring more time and resources than are available.

Indeed, donors supporting services for torture survivors have for some years expressed frustration and concern at the lack of information provided, and the variance in the quality of reports from grantees on the effectiveness and impact of their services and on key outcomes. One consequence, it would seem to service providers, is that donors are less likely to prioritise very vulnerable groups such as torture survivors.

Academic/practitioner-researcher perspectives

There are many reasons why evaluating services for refugees and asylum-seeking people, including torture survivors, is complex and difficult. One difficulty is lack of knowledge and agreement in the field on what are the relevant outcomes for assessment following rehabilitation for people whose lives, health, relationships, livelihoods and family and social networks have been destroyed by torture. Another difficulty is the almost exclusive attention to clinical or specific health outcomes at the cost of other relevant outcomes. A related difficulty is that clinical outcome studies are conducted with this client population in the absence of appropriate, culturally and linguistically valid tools. Those studies and services which do attempt to conduct evaluation largely use tools which are diagnosis-based (focused on specific diagnoses only), developed and standardised in the West for Western, English-speaking populations and where few of those translated into the required languages have evidence of validity.

A further complication is that many clients experience multiple and diverse health difficulties not easily discernible or measured by standard diagnostic tools. Additionally, their needs are often changing, rarely static, with improvements in some areas being accompanied by increasing difficulties in other areas of their life. The impact on health of external and ongoing stressors (e.g. poverty, insecurity, threats to one's safety, racism, homelessness, threat of return to the country where they were tortured, detention in the receiving country, legal processes for determining asylum) experienced by torture survivors is also rarely measured or even acknowledged, though invariably these limit the extent to which services can be effective, or the outcomes reliably measured.

Methods for evaluating services exist but require knowledge and competency to operate reliably. Unfortunately, academics interested in this field may lack the knowledge and clinical experience of providing rehabilitation to torture survivors, and may fail to appreciate the complexity and ethical issues involved. Similarly, practitioners with relevant experience, knowledge and understanding may lack the necessary research skills to conduct effective monitoring and evaluation. Partnerships between researchers/academics and practitioners, though desirable, may be dogged by competing and vested interests, such as on the one hand, seeking funding for research and academic status, and on the other, wanting services which meet the full range of needs that torture survivors present with and which are meaningful to them (culturally, politically etc.)

1.2 Changing landscape

As the field has developed, rehabilitation methods have flourished, legal standards for the right to rehabilitation for torture survivors have been clarified, and professional and service standards have evolved. What has also changed is the political, social and economic landscape in which service providers struggle to provide humane, responsive services for torture survivors and their families. As emphasis is placed increasingly on holding states accountable for their duties to ensure the means to 'as full a rehabilitation as possible', including funding relevant services, other sources of funding are diminishing. Torture survivors' needs, are however not diminishing. Demands for services remain and seem to be increasing while services for, and people prepared and competent to work with, torture survivors seem to be in short supply.

1.3 What helps?

In this context one may ask what is the best way to help torture survivors? It is easy to look towards emerging standards and service quality criteria, and to the dominant discourse of evidence-based practice for answers – for they appear to provide a means to assess whether available resources are used in the best way to help as many torture survivors as possible. The problems remain: standard-setting is there to ensure high quality services, yet seen by many service providers as a stick to punish, diminish and eradicate already scarce and beleaguered services. Evidence-based practice, though desirable, is problematic, given the practical and ethical difficulties of applying the conventional randomised controlled trial to the field of rehabilitation of torture survivors. The pursuit of evidence-based practice is seductive, but it remains a deeply problematic concept, under increasing scrutiny and heavily debated generally in medicine and clinical psychology, and more specifically, in the field of rehabilitation for torture survivors. The reasons are complex and beyond the scope of this publication, but what is important to note is that, decades on, we have yet to establish what helps whom, and how, in the aftermath of torture.

Torture affects individuals, families, communities, and every aspect of society. No method, technique, specific service or intervention alone can address all those effects of torture. While

we may hope for an answer to what exactly 'works', the reality is that we don't know, and service providers and donors may find this hard to acknowledge with each other, particularly when competing for scarce resources. What we do know from what survivors feed back and share, from our clinical practice, and from what research suggests, is that some interventions help some people, with some of their problems, under some circumstances, in some settings, with some changes in some outcomes. We know that 'rehabilitation' is more than techniques, methods and interventions that are 'done to' torture survivors. We know that responding to extreme human suffering is essentially a human interaction – what 'works' is perhaps as much the methods and services we provide, the way we facilitate access to redress, as the way in which we connect and relate to, listen to and bear witness to torture survivors' lives, suffering and survival. In other words, rehabilitation cannot be reduced to services or techniques: it is a much more complex response of many professionals from different backgrounds, guided by different theoretical frameworks and methods, but essentially responding as human beings to human suffering.

1.4 Why monitoring and evaluation?

What is important is that in seeking to answer the question 'what is the best way to help torture survivors', neither service providers nor donors forget that our goals are the same: to ensure high quality care and services to torture survivors and their families. Our monitoring and evaluation methods and systems should be designed towards this one goal.

Monitoring and evaluation are, then, not sticks with which to beat service providers and practitioners, nor carrots to entice them to do what they already do (with passion, commitment and often for little or no remuneration). Monitoring and evaluation are tools to help service providers to work towards providing the best care possible, with the available resources, methods and skills, whilst seeking to improve their services wherever possible.

These guidelines are intended to help organisations work towards establishing systems to ensure the highest quality services, providing some tools to facilitate this. Corresponding guidelines for donors aim to help improve their understanding of the complexity of monitoring and evaluation in this field, and of ways in which they may facilitate improved monitoring, evaluation and reporting by service providers.

1.5 Key principles underlying this guidance

The guidance for monitoring an evaluation is based on key principles, as summarised below in Box 1:

Box 1: Key principles for monitoring and evaluation of rehabilitation services for torture survivors

- **Client-centred**
  All monitoring and evaluation systems, practices and activities should ensure the best interests of clients as the main priority. They should be respectful to clients, non-intrusive, and non-burdensome, acknowledging their impact on clients. They should not hinder therapeutic contact with clients.

- **Ethical**
  All monitoring and evaluation systems and practices should adhere to ethical principles, including the principles to do no harm and to protect torture survivors from harm, from exploitation and from any breaches of confidentiality.

- **Accountable**
  Monitoring and evaluation should be seen as a means to ensure accountability: to clients, to donors and to other stakeholders.

- **Meaningful**
  Monitoring and evaluation should be meaningful to clients, relevant to their needs, their experiences and make sense to them in light of the torture and other hardships and injustices they have experienced, or are still experiencing.

- **Respectful and enabling**
  All monitoring and evaluation should be respectful to torture survivors and their families, and seek to enable them to share their views and to provide feedback on services they receive, without adverse consequences.

- **Participatory**
  Monitoring and evaluation should be a collective task and a responsibility which engages all staff and all management

- **Involving of torture survivors**
  Monitoring and evaluation systems and practices should consult torture survivors on their views of those systems and practices and ways to improve them. Torture survivors must not be seen as passive recipients of monitoring and evaluation activities and measurements which are 'done to them', but as active participants whose views and experiences of the organisation's systems and practices, including monitoring and evaluation, are crucial to developing ethical, respectful and meaningful systems.

- **Professional**
  The processes of monitoring, evaluation and reporting are vulnerable to ethical and professional breaches which must be avoided, with professional integrity being maintained throughout.

2. Using the handbook

This section addresses the questions of who can use the guidance and resources in this handbook, and in what way.

2.1 Who is this handbook for?

The guidance and resources in this handbook are for managers and practitioners, those responsible for monitoring and evaluation of rehabilitation services for torture survivors.

They are written for access by a range of people with different backgrounds (management, clinicians, researchers, fundraisers etc.), so that all responsible for ensuring or supporting effective monitoring and evaluation have some overall understanding of the breadth and complexity of the task. Nonetheless, it is important to recognise that monitoring and evaluation of multidisciplinary rehabilitation services, which address health, social, welfare and legal needs, are typically diverse, complex and often offered in combination, require a reasonably high level of specialist knowledge and skills.

It is essential that those who are responsible for implementing the suggested guidelines have some prior knowledge and expertise in monitoring and evaluation, specifically within the health and social care fields. In the absence of this, it is strongly advised that external expertise be secured to guide and supervise those responsible for implementing monitoring and evaluation systems and using analyses for reporting purposes. A consideration of resources required would therefore be necessary to ensure the meaningful and sustainable implementation of this guidance.

2.2 Knowledge, skills and resources required for monitoring and evaluation

Monitoring and evaluation are complex activities requiring a range of knowledge, skills and resources. These activities cannot be carried out without institutional support and engagement of management and all staff.

There are three broad principles in ensuring effective monitoring and evaluation systems, summarised below:

Key principle 1: Ensuring adequate resources

- Often, rehabilitation centres function on very limited resources with most staff resources concentrated in direct service delivery, and with little time for effective monitoring and evaluation. In some cases, a single person, for example a monitoring and evaluation officer, may be allocated the responsibility for monitoring and evaluating of the activities, services and projects delivered by the whole organisation. Sometimes, there is no one allocated the task of leading or overseeing monitoring and evaluation. Furthermore, smaller organisations with less staff resources will be less able to design and deliver an elaborate monitoring and evaluation system.
- Nevertheless, all organisations should ensure that, at minimum, there is a monitoring and evaluation strategy and a system relevant to the overall goals of the service. This would require that resources are sought and allocated to first, design and then, to implement such a system.
- Ideally, each organisation should have a small task-force, team or committee specifically for designing, implementing and developing such a system. This group should comprise, at

minimum, a senior clinician/clinical director, a senior researcher with a background in health research and research methods, persons responsible for data entry and clinical records, and a person with a background in database development and implementation.

- Service providers can also ensure that staff time in engaging with monitoring and evaluation activities (e.g. seeking information from clients, recording data, using monitoring tools etc.) is seen as integral to each staff member's job description and work plan, with the time required for such activities to be factored into daily work practices, and monitored by line managers.

Key principle 2: Ensuring competency: adequate knowledge and skills

- The skills required to develop and to implement basic systems for monitoring and evaluation are common in different fields, but more complex skills and knowledge are required to develop, implement and maintain appropriate systems for monitoring evaluation which are relevant to working with torture survivors.
- Basic knowledge of monitoring and evaluation should be a pre-requisite for all managers and staff engaged in direct service delivery.
- Complex knowledge and skills required to develop, implement and maintain appropriate systems for conducting evaluation will often require, at the very least, a senior clinician/ researcher and an information and communications technology specialist.
- Where an organisation does not have the necessary knowledge and skills, they may well be advised to seek external consultation or collaborative partnerships or supervision from experts locally, for example from other organisations in the region, or from academic institutions, etc.

Key principle 3: Ensuring ethical practice

- Whilst enormously challenging to implement effective monitoring and evaluation systems with limited resources, it is considered poor and unethical practice to implement a system and to use methods and tools in the absence of relevant required knowledge and competency; or without knowledge or skills in appraising their limitations and risks, and in analysing and interpreting results. When service providers feel pressured to show that they are conducting some monitoring and evaluation, systems may be developed to collect large amounts of data from clients – but with no plans, or capacity, skills or organisational commitment to do anything with the data – which is considered burdensome for clients and staff, and unethical.
- Sometimes, service providers may cut corners, because of organisational constraints and/ or because of the absence of appropriately qualified and experienced staff with time and resources allocated to carry out effective monitoring and evaluation. While short cuts are sometimes necessary and may appear to satisfy donors, they are risky. The process of collecting information, analysing, interpreting and reporting is a task that should not be underestimated either by service providers or by donors. Short cuts can obscure unethical practice, where (apparently) satisfying donors at any cost takes precedence over ethical and professional practice, inevitably at the cost of service users. Hence, it is important that monitoring and evaluation activities are not undertaken half-heartedly, with practices lacking an appropriate level of rigour, carrying risks of ethical breaches.
- As stated earlier, where the necessary knowledge and skills do not exist within an organisation, management should take action to seek funds to recruit appropriately qualified and experienced people in the future; to plan for the development of monitoring and evaluation systems when expertise and resources are identified and secured; and in the meantime to seek consultation from those appropriately qualified and experienced, where relevant. It is important to communicate to donors the steps being taken to address any difficulties.
- Management should also prioritise the establishment of a monitoring and evaluation system within its competency, as a starting point, for example, to focus first on effective monitoring,

then on evaluation; perhaps to start small, and to develop systems and monitoring and evaluation projects with time as resources and relevant skills and knowledge can be secured (e.g. in the recruitment of appropriate staff, in seeking external consultants, in seeking supervision from local/regional experts).

- Service providers should be vigilant to risks to professional and ethical practice in monitoring and evaluation and seek to operationalise key principles for ensuring effective monitoring and evaluation systems.

These guidelines are intended to show service providers what can be done, and the knowledge and skills required, for each type of monitoring and evaluation activity, so that ethical practice is promoted and that organisations are able to plan the resources needed for effective monitoring and evaluation systems relevant to their work.

2.3 How is the handbook organised?

The handbook is organised into key sections, each inter-linked:

Section 3 summarises relevant standards for rehabilitation in international law in relation to torture survivors and summarises key professional standards relevant to service provision. Quality criteria, integrating legal and clinical standards for rehabilitation services, are also defined.

Section 4 provides a framework for designing a system for measuring overall quality of rehabilitation services, outlining key responsibilities for management in ensuring appropriate governance for monitoring and evaluation.

Section 5 considers the factors which may shape the design of rehabilitation services, including the national context. Key components of rehabilitation services are identified, and a small sample of service models is described. It is very important to identify and understand the design and model of a service because they largely influence the approach to monitoring and evaluation which is undertaken by the organisation.

Section 6 focuses on monitoring rehabilitation services for torture survivors. It describes the steps to undertake when designing, developing and implementing a monitoring system which includes both routine monitoring and audit projects.

Section 7 focuses on conducting service evaluation. It describes different forms of evaluation, and steps to undertake in identifying quality standards and evaluation questions as a starting point to designing and implementing service evaluation projects.

Section 8 focuses on clinical outcome evaluation, a particular form of evaluation. Key ethical considerations, methodological challenges and good practice are addressed.

Section 9 addresses one of the purposes of conducting monitoring and evaluation, reporting to donors on client information, service activities and monitoring and evaluation outcomes.

2.4 How best to use the handbook?

The process of establishing and developing monitoring and evaluation systems and practices is continuous, since services evolve to respond to changing contexts, including local contexts, client needs and funding opportunities. As such, these guidelines and resources can be used at any stage of an organisation's life, to initiate new monitoring and evaluation systems and practices or

to review existing ones. During the design and establishment of services, the guidelines may be used to build in monitoring and evaluation systems.

Ideally, a small group of people, comprising senior managers, senior clinicians and those with expertise in information management systems, led by someone with a background in monitoring and evaluation of multidisciplinary health and social care services, could guide the organisation's development of appropriate systems. In the absence of such resources, or of opportunities for existing staff to commit such time, management may need to decide what initial steps can be taken to allocate such responsibility appropriately. The guidance provided here is intended to support the work of such a team or committee, and the tasks facing management.

The resources in the appendices provide examples of different monitoring and evaluation tools (not standardised measures, which would have to be obtained from the relevant authors or publishers in each case) which could be adapted and used by organisations.

2.5 Summary

- **Leadership:** Ensure there is a strategy for designing, implementing and developing effective monitoring and evaluation systems. Nominate a senior person with specialist background or knowledge relevant to monitoring and evaluation, to consider these guidelines and to lead the review process for the organisation by forming a task force, working group or committee on monitoring and evaluation.
- **Understanding the framework:** Read through the whole guidance first, including the introduction where key principles are outlined, since the sections are interlinked and provide a conceptual framework to monitoring and evaluation approaches relevant to rehabilitation services for torture survivors.
- **Identifying gaps, areas for improvement, strengths:** Focus on each section, depending on which area is identified by the organisation as needing discussion, review and improvements. Identify areas of good practice, areas for improvement, and gaps in systems and practices.
- **Tools:** Use the tools provided in the appendices, if appropriate to the service design and goals, and adapt to the organisation's requirements.
- **No perfect system:** Remember that monitoring and evaluation, particularly in this field, are not easy tasks and there is no simple, quick or perfect way of conducting monitoring and evaluation of torture rehabilitation services.
- **Discuss with colleagues:** Remember that the field of monitoring and evaluation is very complex, particularly when evaluating a range of health, social and legal services, as is common in rehabilitation services for torture survivors. Discussing with colleagues and encouraging all staff to reflect on these activities and challenges is advisable.
- **Serious undertaking:** Monitoring and evaluation are a serious undertaking and should be approached as tasks, or token gestures, to fulfil donor requirements. They are tasks to enhance service delivery to torture survivors. Those shortcuts which compromise ethical practice must be avoided. Organisational decisions made on developing and implementing such systems must be scrutinised to ensure they do not lead to practices which breach professional ethical standards or national or international legal standards. The guidance here will not be helpful if only 'dipped into' randomly, without considering key principles and the whole framework for monitoring and evaluation.
- **Continual reflection:** Monitoring and evaluation is a continuous process of ensuring quality and accountability. This requires regular analysis, reflection and steps towards improvements. It is advisable to re-visit the guidance from time to time, to further develop the organisation's monitoring and evaluation policies and practices.

3.Quality of rehabilitation services

While rehabilitation services for torture survivors may differ in components, emphasis, philosophy and key methods, the common aim of such services is to provide rehabilitation to torture survivors, addressing their specific needs. The question of how we ensure that rehabilitation services are of a good standard and offer high quality services is the impetus for developing appropriate monitoring and evaluation systems.

This section outlines standards in international law and in the health and social care fields which are relevant to rehabilitation services for torture survivors, and defines the key criteria (standards) for assessing the quality of those services. The purpose and nature of monitoring and evaluation are elaborated, highlighting the cyclical nature of monitoring and evaluation activities to ensure the continuing quality of services provided.

3.1 Purpose of monitoring and evaluation

The purpose of monitoring and evaluation is broadly to address the questions:

- Are the services offered to torture survivors are of an appropriate standard and do they meet quality criteria?
- Do those rehabilitation services make any difference to torture survivors? In what way?

These questions may be further elaborated as:

- How do you know that your services meet accepted/agreed standards?
- How do you know that your services meet quality criteria?
- What does your service achieve?
- How does your service make a difference/have an impact? On whom?
- How effective is your service? In what ways? For whom?
- What is the best use of available funds?

Service commissioners and funders may also ask these questions in different ways. While each question is different and will be answered in different ways, each relates to the fundamental question: "Does your organisation do what it says it does and set out to do?"

3.2 Standard-setting

To address the overall question of "Does your organisation do what it says it does and set out to do?" we might ask how do we decide what rehabilitation services should be doing. Should services only be expected to demonstrate that they achieve their own goals, as they set them, regardless of established standards in the field? Or should services consider standards established in international law, in professional practice and other relevant standards as a way of benchmarking?

The pursuit of high quality rehabilitation services for torture survivors is a process which requires exploration of what high quality means in this context and of which standards are relevant to assessing quality of torture rehabilitation services. In this field, there are two types of standards essential to understand, elaborated below.

3.3 International legal standards for rehabilitation services

According to international human rights law, as recently defined in General Comment 3 of the United Nations Convention Against Torture[1], States parties have an obligation to ensure the following:

- **Available:** to ensure the establishment in the State of "effective services and programmes".
- **Accessible:** "without discrimination and regardless of a victim's identity or status within a marginalized or vulnerable group, including asylum seekers and refugees. Torture victims should be provided access to rehabilitation programmes as soon as possible following an assessment by qualified independent medical professionals. Access to rehabilitation programmes should not depend on the victim pursuing judicial remedies".
- **Appropriate:** "tailored to the needs of torture survivors and their families; and available in relevant languages"
- **Holistic:** "meeting range of needs (torture survivors and families)"
- **Interdisciplinary:** "providing services including medical, physical, psychological, social, legal, re-integrative services; community and family-oriented assistance and services; vocational training; education"
- **Specialist:** meeting the specific needs of torture survivors and their families
- **Guarantees safety:** Provided in a way that guarantees the safety and personal integrity of the victims and their family
- **Time-sensitive:** Care provided as soon as possible in the initial aftermath of torture and within longer-term services
- **Service provider:** obligation to "provide for the means for as full rehabilitation as possible can be fulfilled through the direct provision of rehabilitative services by the State, or through the funding of private medical, legal and other facilities, including those administered by non-governmental organizations. States obliged to ensure that no reprisals or intimidation are directed at victims; and that the victim's participation in the selection of the service provider is essential".

3.4 Professional and ethical standards for rehabilitation services

Each profession in the health and social care fields has its own sets of ethical and professional standards for practice. While they may vary in wording and emphasis, the core ethical principles and standards of professional practice are largely similar. According to these, rehabilitation services should:

- **Do no harm:** be provided by those who behave professionally and without coercion, threat, exploitation or harm towards the client and their family
- **Non-discrimination:** provide clear criteria for inclusion and exclusion but should not discriminate against clients within the overall remit of the service on any basis other than clinical need, including on grounds of gender, sexuality, ethnicity, 'race', age, disability etc. (as defined also within national legislation)
- **Competency:** be provided by those qualified and competent to do so, where those who recognise the limitations of their competency do not act beyond their level of competency, risking harm to the client and/or their family
- **Confidentiality:** ensure confidentiality, having regard to clinical duties which arise when there is a risk of suicide, risk of harm to the individual or to others, or child protection concerns
- **Informed consent:** seek informed consent – such that clients fully understand what they are being offered, its limitations, their right to withdraw, provide feedback, or make a complaint without adverse consequences to them or family members from the organisation

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1 General Comment No. 3 (2012): Implementation of article 14 by State Parties, CAT/C/GC/3, 13 December 2012.

- **Referring on:** be provided by those who are competent in being able to know when to sign-post and refer clients onto other relevant services, where necessary and where available
- **Timely:** seek to reach those most in need in a timely way and provide services, including initial crisis care wherever possible, and medium to long-term care as required

3.5 What is quality?

Quality typically refers to the overall framework of standards for service delivery. It can be thought of as encompassing:

- Standards in international law for rehabilitation services;
- Standards as established in professional and ethical codes; and
- Standards specific to rehabilitation service delivery.

Quality can be defined in many ways and have different meaning for those from different professional disciplines which may place different values on different aspects. It is a multidimensional concept and comprises a complex set of inter-related standards.

High quality services are not those that meet one or two quality standards (detailed later in section 3.6), but those which address all key aspects of quality. Often, services, donors and others put emphasis only on clinical outcomes, or on effectiveness, without considering the many aspects of rehabilitation services and activities which also impact on torture survivors' experience of the care they receive, and on their progress, or lack thereof.

It is well-established in the healthcare field that the way in which services are structured and delivered can influence the process and outcome of care. It is also established and widely accepted that the process of care (e.g. therapeutic relationship with a clinician, how clinicians interact and relate to clients) and processes of service delivery (e.g. how clients are received in a service, how they are involved in developing their own care plans, their experience of waiting times, how different service components are coordinated and delivered etc.) can influence clients' experiences of services, and of the outcome. Therefore, it is essential that any system of monitoring and evaluation consider how to address the overall quality of services, assessing the different standards and not just focusing on effectiveness or clinical outcomes as the sole standard of quality.

3.6. Quality criteria for rehabilitation services

Most definitions of quality have the following common factors: fairness and accessibility, effectiveness, appropriateness and acceptability to clients. Quality criteria, which take into account standards for rehabilitation in international law and standards common to professional and ethical codes, include those below. Under each criterion (standard), several example questions are provided to illustrate relevant indicators[2]:

Criterion 1: Safety and personal integrity of clients and staff working with them
- Do services protect clients from avoidable harm and, if so, how?
- How have services responded when clients have not been protected from harm?
- How do services protect those clients at risk of suicide, self-harm or harm to others, including minors?
- How do services protect those clients in detention, where services are offered within detention settings?

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2 Based on ongoing research, conducted by the first author, on the development of indicators for the right to rehabilitation.

- How do services protect the confidentiality of personal, clinical records of clients and how are breaches addressed?
- How do services protect the security of professional communications (paper, telephone, email etc.) to protect client confidentiality and safety, and to protect staff safety?
- How does the service protect the best interests of the client and involve them in decision-making about their care and services they receive?
- How do services protect staff working with torture survivors and their families from harm, intimidation, threats and other abuse?
- How do services ensure the safety and well-being of staff working with torture survivors?

Criterion 2: Appropriate and acceptable
- How thoroughly does a service assess the needs of torture survivors and their families?
- To what extent do services use established standards in conducting health assessments of torture survivors and documenting torture (e.g. United Nations' Istanbul Protocol[3])?
- How do providers ensure that services are tailored to and address the needs of each torture survivor?
- How do providers ensure that services address the needs of families and communities affected by torture?
- Do services provided address the range of needs of torture survivors (immediate and long-term needs) and their families??
- Are services provided holistic, specialist and interdisciplinary? How is this ensured?
- Are service providers/practitioners specialists in rehabilitation for torture survivors?
- Are practitioners qualified and competent in providing specialist rehabilitation for torture survivors?
- How relevant and appropriate is the service design, and the services provided, given the client population, their experiences of torture, their strengths, resources and needs?
- How do services make decisions about which clients to prioritise when demand far outstrips supply? Are services appropriate for those prioritised?
- Why is a particular service or approach provided: does it meet the needs of clients; is it relevant to their specific needs and what clients say they need; is it acceptable to clients? Is it in the relevant languages of clients?
- How relevant and appropriate are services to clients' gender, age and their cultural, linguistic, religious and ethnic backgrounds?
- How relevant and appropriate are services to clients' legal needs and context (e.g. need for asylum, resettlement, redress)
- How do clients experience the care and services they have received?
- What do clients find appropriate, or inappropriate; what do they value in services they have received, and why?
- How acceptable are the services overall to torture survivors, their families and their communities?

Criterion 3: Effectiveness
- Do services enable positive change in clients' difficulties as clients report them/as practitioners assess them? How?
- How effective is the service in improving clinical outcome?
- What changes are seen in which types of outcomes, following which interventions for which

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3 Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Professional Training Series No. 8/Rev.1. (2004). United Nations: Geneva and New York

torture survivors?

- Which particular therapeutic approach or a project, or component of a service is effective? In what way?
- How is effectiveness defined within a service, with which models used and against which goals?
- To what extent has the organisation met their aims and goals in delivering the services as planned?

Criterion 4: Impact

- What are intended and unintended benefits, consequences or costs (outcomes) of the services/ activities to clients, their families, communities?
- What are the intended and unintended benefits, consequences or costs of services/activities to referrers (e.g. legal representatives, other NGOs)?
- What is the short, medium and long-term impact of services?
- What is the wider impact of rehabilitation services (e.g. contributions to knowledge in the field)?
- What is the wider impact of rehabilitation activities (e.g. prevention activities) nationally, or on the local community, health and social care and legal professionals, on policy, practice etc.?
- What other benefits (or challenges) arise from delivering a service/conducting a service-based project?

Criterion 5: Coherence

- How coherent, integrated and coordinated are the different service components?
- How do the rehabilitation services relate to and complement other services (e.g. services provided by the state, by NGOs, INGOs)?
- How compartmentalised are services and how does the service design enable holistic care to be provided to torture survivors?
- How effective are referral pathways (internally between difference service components and externally with other agencies) in ensuring that clients receive appropriate and timely care?

Criterion 6: Accessibility

- How are torture survivors, wherever they are (e.g. in detention settings, mainstream healthcare services, refugee camps, communities), and whatever their legal status, identified and assessed as needing rehabilitation services?
- Which services are used by which client groups? Are there any client groups who are not accessing services? Why?
- Are all services accessible to torture survivors and their families, based on their rehabilitation needs and not on any other factor or their ability to pay?
- Are all services accessible in the language of the torture survivor/with an interpreter where required?
- Which services/service components are most or least accessible and used by different client groups? Why?
- How accessible are services geographically and in terms of location and transportation requirements?
- How accessible are the premises of the services to those with disabilities?
- How accessible are services to those stigmatised in society (e.g. women who have been raped, those with mental health difficulties, those from marginalised communities)
- How accessible are services to those who fear threats, reprisals or arrests if they seek to report torture and to seek relevant rehabilitation services?

- How accessible are services to those who were tortured in the same or nearby area, and who may fear returning to those places?
- How accessible are rehabilitation services to those in detention or other secure settings?

Criterion 7: Fairness
- Are relevant services equally available to all in need?
- Are services non-discriminatory?
- How are inconsistencies in service access and delivery to different groups justified by the service providers?

Criterion 8: Timely
- How well do services ensure that torture survivors are promptly identified?
- How promptly can torture survivors be seen for an initial assessment from the point of referral? How long do they have to wait to be seen? Why?
- How long do torture survivors have to wait before they can commence therapeutic or other rehabilitation services? Why?
- How long do torture survivors have to wait to be referred to relevant services (internally in the organisation, or externally to other agencies)? Why?
- How promptly are torture survivors who are most vulnerable and at risk of suicide or of harm to self or others identified, offered services or referred on?

Criterion 9: Cost-efficiency
- What resources are available to provide rehabilitation services and how adequate are they? Why?
- How well are available resources utilised to achieve the intended results?
- How cost-effective is the overall service; or service components or projects?

Criterion 10: Sustainability
- How likely are the benefits from services to be sustained in the longer term (e.g. for clients, referrers, other stakeholders)?
- How likely are the benefits from rehabilitation-related activities (e.g. clinical supervision, consultation or training for health professionals in other organisations or in state-provided health services to provide rehabilitation to torture survivors) to be sustained in the longer term?
- To what extent is the service design sustainable (e.g. in light of internal or external changes, developments or threats)?

3.7 Quality measurement

Quality measurement can be used for external reviews, for example by an external body for the regulation of an organisation, or for accreditation purposes, or for performance management or other reasons. This is different from quality measurement to enhance the overall quality of services.

Definition of quality measurement: The ongoing monitoring and evaluation activities and methods used to support an organisational process of continuous analysis, reflection, learning and improvement to ensure quality standards of rehabilitation services for torture survivors, their families and communities.

The standards outlined in the preceding sections are examples of standards against which

services can be monitored and evaluated, to assess the overall quality of services and to identify what needs to be improved. Since quality is multidimensional, no one approach to measurement will adequately capture the quality of a service and hence different methods of measurement are required to fit different questions assessing different standards. However, in order to measure whether services meet certain standards, it is essential to establish indicators. Again, no one set of indicators will provide a definitive assessment of the quality of a service. Ideally, indicators for the quality of torture rehabilitation services could be applicable globally, though some standards would require indicators specific to the service, and the local and national context.

The process of defining indicators is not easy, though the questions listed under the quality standards in section 3.6 provide some guidance on relevant indicators of service quality. Unfortunately, in the field of rehabilitation for torture survivors, there is a wide variation in views on what those indicators should be, making comparisons or transferability of good practice across services less likely. There are various standard approaches to defining indicators of quality services in the health and social care field but these too are controversial in the field of rehabilitation for torture survivors. Broad methods of developing indicators include the use of research-based evidence; the use of consensus-building amongst expert informants; use of clinical guidelines and good practice guidelines to identify indicators; and using practice-based evidence on what is meaningful 'on the ground' to practitioners and clients.

The measurement of quality is not a one-off activity. Ensuring quality services is not an easy task, especially because it requires time, resources, effort and commitment to continuously improve. It is a task which requires managers and practitioners to work together and to share a common language with each other, and with donors. It requires all parties to honour the complexity of the nature of rehabilitation for torture survivors.

The task of ensuring quality is also difficult because quality is a moving target. The definition of quality and the emphases may change with time, in response to changes in national and international legislation; changes in the professional regulation for professionals providing rehabilitation (which also varies tremendously from country to country); and developments in the health and social care and legal fields relevant to torture rehabilitation. Thus, it is important for service providers, practitioners and donors to be aware of these developments, and to work together in reaching a common understanding of what are quality services, to ensure, together, that torture survivors are able to receive the services they need, and services that they are entitled to.

The methods of measurement used in monitoring and evaluation need regular review to ensure they capture what they are intended to, or to explore other methods better suited to assessing the overall quality of services. As Einstein is reported to have once said, 'not everything that counts can be counted, and not everything which is counted counts'. It is important to consider different ways of assessing quality, so that all aspects of quality can be assessed. The methods used in monitoring and evaluation include both qualitative and quantitative (addressed in sections 6, 7 and 8), and a range of routine monitoring activities and audit projects, as well as the use of client feedback and client complaints. Information on critical incidents can also be used to inform the process of assessing the quality of a service.

3.8 Summary
The need for clear standards for rehabilitation services for torture survivors is an important step in developing monitoring and evaluation systems. This section has outlined key standards,

combined from international legal standards on the right to rehabilitation, professional and ethical standards and quality criteria for services. Whilst much work remains to be done in the field to articulate indicators for those standards, the diversity of services and service settings require that indicators vary depending on context. Importantly, monitoring and evaluation should be seen not as an adjunct to core service provision, but as a 'whole systems approach' integral to developing high quality rehabilitation services.

4. Designing a system to measure overall quality

The main aim of designing a monitoring and evaluation system is to ensure the overall quality of rehabilitation services. In other words, a system has to be able to, at the very least, address key questions such as:

1. Are the goals of services met, and how?
2. What is the overall quality and standard of services provided?
3. What difference do services make to clients and other stakeholders?

Designing a system of monitoring and evaluation for any torture rehabilitation service requires some preparation and ongoing investment in time and energy to monitor, maintain and develop it.

4.1 Responsibilities for all staff and management

Designing a system to measure overall quality of a service cannot be left to one person. It requires concerted effort and engagement from all staff to understand why such systems are necessary and what are required for such systems.

It is always helpful to reiterate to staff the key purposes of establishing effective monitoring and evaluation systems. Common reasons are summarised in Box 2 below:

Box 2: Why establish monitoring and evaluation systems?

- Serving the interests of torture survivors and their families
- Involving clients or ex-clients in providing feedback, influencing how services can be improved
- Ensuring the quality of services: meeting standards
- Learning about who uses our services
- Learning about clients' experience of services, benefits, impact etc.
- Identifying service gaps, strengths and areas for improvement
- Identifying gaps or shortfalls in particular skills or competencies, or training or supervision needs for skills development
- Improving services: structures, procedures, processes and practices
- Reflection and professional learning and development
- Reflection and organisational learning and development
- Raising awareness of staff, stakeholders and clients on quality of services
- Contribution to knowledge in the field of rehabilitation for torture survivors
- Accountability to clients and other key stakeholders
- Accountability to donors

4.2 Responsibilities of management

Each organisational structure varies according to the nature of the organisation, its local context, national legislation which may dictate governance structures (e.g. for charitable organisations or NGOs), national policies which may determine service structures and governance (e.g. within state health services), local and national needs and available resources. Central to all organisations offering services to survivors of torture is the need for governance structure and systems, within

its own organisational structure, to ensure the quality of those services, and to ensure appropriate structures, systems, resources and processes for monitoring and evaluation.

Implementing, and maintaining, monitoring and evaluation systems and practices is a process which requires time and energy. It can involve triumphs, struggles and, at times, challenges which seem insurmountable and burdensome. It is a process which necessitates difficult ethical decision-making about what is a priority for monitoring and evaluation in the organisation, and whether short-cuts are unacceptable for example, if they compromise client safety or fairness of services. It is important to remember that ensuring quality of rehabilitation services requires continuous effort, a collective action across the organisation of 'pulling together in the same direction', with shared values and purpose.

Governance structures

A governance structure for monitoring and evaluation may be the Board of the organisation which would be collectively responsible (e.g. if the organisation and Board are small in numbers) for ensuring appropriate monitoring and evaluation systems. In larger organisations, the governance structure may be a sub-group or sub-committee of the Board, ideally with those individuals with experience, knowledge and skills relevant to monitoring and evaluation of services for torture survivors. In most organisations, the senior management team, or equivalent, may be the structure responsible collectively for creating an appropriate system to ensure that monitoring and evaluation are carried out effectively.

In summary, a governance structure for ensuring monitoring and evaluation is the management (e.g. all senior management and Board members or a sub-group, who act on behalf of the whole management) who share a collective management, professional and ethical responsibility for ensuring that torture survivors and their families receive services which meet agreed standards. The context of each service will dictate the most appropriate governance structure.

Governance systems

It is the responsibility of management to establish a clear governance system which is supportive, enabling and not unduly burdensome, to ensure effective and appropriate monitoring and evaluation within the organisation.

It is also the responsibility of management to identify competent organisations or individuals, including academic institutions, to be consulted to ensure that the relevant knowledge and competencies required to establish monitoring and evaluation systems are available. Fostering such relationships and possible partnerships could also facilitate the development of appropriate skills, relevant to monitoring and evaluation, within the organisation.

Key management responsibilities and good practice include the following:

1. Agree standards and benchmarks for the services
- Identify standards applicable to the services being offered
- Ensure that standards are clearly articulated to all staff
- Ensure that standards are tied to the goals of the service
- Ensure benchmarks are S.M.A.R.T (Specific, Measurable, Attainable, Relevant, Time-bound)

2. Formalise an organisational strategy for monitoring and evaluation
- Consult staff, managers, clients and other stakeholders
- Identify skills, knowledge and resources needed to develop, implement and maintain

monitoring and evaluation systems
- Clarify which roles and posts are required, and the responsibilities of the relevant post-holders
- Identify resources required for those posts
- Identify reporting requirements: what is needed as information for donors and stakeholders
- Identify existing good practice in the organisation, and in the field
- Identify opportunities and challenges for the organisation
- Identify current and future risks (internal and external) to developing, implementing and maintaining monitoring and evaluation systems and practices in the organisation
- Establish systems to review incidents, complaints and feedback from clients and stakeholders to enable organisational learning
- Establish indicators and a management system to monitor the implementation of the strategy

3. Create and nurture an organisational culture of continuous monitoring, evaluation and improvement of services
- Engage staff at the outset in developing a strategy for monitoring and evaluation, ensuring they are aware and fully understand the reasons for conducting monitoring and evaluation (for client care; for organisational development, for accountability to clients, donors and other stakeholders)
- Demonstrate meaningful engagement and commitment from management in monitoring and evaluation of services – talk to staff and clients, take an active interest in how services work, how they are delivered, what are daily challenges, areas of good practice
- Reiterate the goals of the service, the core tasks, and how monitoring and evaluation can support the organisation in achieving its goals

4. Ensure all staff are engaged and committed to ensuring quality services, and to monitoring and evaluation
- Encourage staff to share their doubts or reluctance to engage in monitoring and evaluation activities
- Take time to explore staff feedback, frustrations and concerns about monitoring and evaluation activities they are involved in
- Provide feedback from monitoring and evaluation activities and reports to staff in clear terms, engage in reflection and discussion of feedback, and contribute to future planning and identifying changes needed for continuous improvement of services
- Value staff, providing them with positive feedback, support and encouragement
- Support staff when they receive negative feedback from monitoring and evaluation reports about services their team provide
- Ensure staff understand that monitoring and evaluation are not individual performance management tools but activities to improve overall services
- Recognise the complexity and enormous challenges involved in providing rehabilitation services to torture survivors, and acknowledge the experience of monitoring and evaluation as an 'added demand' or 'bureaucratic activity' on practitioners and clients
- Remind staff that monitoring and evaluation are not a management stick, or a donor-driven activity designed to undermine and to punish them but a tool and an approach to collectively enhance services for torture survivors to meet their needs – the core task of rehabilitation services

5. Development of an appropriate structure
- Identify a structure to develop, implement and maintain monitoring and evaluation systems. Such as structure may depend on staff resources and skills. It could be a taskforce, a

committee, a working group, including relevant senior managers, responsible for the design, implementation and development of monitoring and evaluation systems.

- Identify key skills needed in such a structure. This could include skills in management, project management, research skills, clinical skills, information technology skills, data entry skills etc.
- Define the remit of this group/structure, and the roles and responsibilities for each member
- Decide the regularity of meetings and reporting obligations (to senior management and/or to the Board)
- Establish how the skills mix of this structure will be reviewed periodically to ensure all relevant staff are included. It is important that the group does not become too cumbersome, hindering effective decision-making.

6. Clarity on the roles of and responsibilities allocated to individuals

- Identify who will do what: what are the roles and responsibilities of managers, practitioners, administration staff, data entry staff, researchers etc.
- Ensure that duties for monitoring and evaluation are articulated in the job descriptions for all relevant posts
- Ensure that annual appraisals consider two-way feedback from staff and their line manager on their roles and responsibilities in relation to monitoring and evaluation
- Ensure that the roles of managers at different levels of responsibility are clearly articulated, including the roles of Board members
- Reiterate that managers and the Board share a collective responsibility to establish, develop, implement and maintain appropriate monitoring and evaluation systems
- Clarify which specific aspects of monitoring and evaluation systems each manager and Board member is accountable for, as well as sharing overall accountability with each other.

7. Development of systems for the implementation of monitoring and evaluation (see sections 6, 7 and 8 for further details)

- Consult clients and affected communities on their priorities for rehabilitation services, their experiences of the service and their positive and negative feedback and complaints
- Consult staff and each service component/team on what are the goals of their service, what are their priorities for monitoring and why, what are their priorities for evaluation and why, what feedback do they need on their services etc.
- Consult managers of each service component (e.g. welfare services, legal advice, physiotherapy services) and organisational directorates (e.g. clinical director, fundraising and communications director) on their needs and priorities
- Ensure staff and managers understand mutual and differing needs for monitoring and evaluation. It can help to hold meetings, viewing presentations from different service managers and staff groups to facilitate shared understanding of priorities for monitoring and evaluation
- Agree which key questions, related to which quality standards, are important for the organisation to address in a monitoring and evaluation system. It is advisable to hold meetings across the organisation, and to involve relevant services and staff in deciding the final set of key questions. These can be reviewed annually, as more frequent changes may not be easy to integrate into the design of the data collection system. It is important that questions agreed are scrutinised to ensure that priorities for monitoring and evaluation are identified, whilst being realistic about what is measurable, at that stage in the organisation's development. Avoiding a burdensome and unwieldy set of questions and data requirement will help a workable monitoring and evaluation system to be established, which can then be refined annually.
- Agree the minimum data set with relevant managers or senior staff, administration staff, data entry staff and others, of information needed for the whole organisation. Such data may

change with time, and may vary according to who needs the information for what purpose. For example, some information may be required by clinical service managers to help decide the changing patterns of service use by different client groups; the changing health, social, welfare and legal needs of clients; the efficiency of services provided; the number of clients who voluntarily stop using services etc. Information required may depend on what donors require for reporting purposes (e.g. numbers of clients seen, numbers offered treatment, numbers who were themselves perpetrators, the outcomes of services or a specific project).

Often, agreeing minimum data required by an organisation will involve many discussions across the organisation to reach a consensus on what is essential to collect, and for what purpose and for whom. This process must not be rushed and it is good practice to review the minimum data set required on an annual basis, to ensure that vast amounts are not routinely collected without review, which is unnecessary or not used for any purpose. This can dissuade staff from cooperating with obtaining and recording information, and cause frustration, resentment and resistance to future monitoring and evaluation activities.

Establishing minimum data is also difficult when many donors supporting the same service have different requirements. It is useful to discuss with donors the difficulties this may raise and what would be an appropriate way forward in agreeing the minimum data set.
- Ensure that all staff have clear guidance and training, as necessary, on what is required for data recording, where and how
- Ensure there are defined roles and responsibilities allocated to staff for competent data entry

8. Establish systems for the analysis of quality and monitoring and evaluation information
- Identify who will be responsible for ensuring that the analysis of quality-related information and data is conducted in a timely, professional and competent way
- Establish key knowledge, skills and experience needed by staff responsible for analysis of information
- Monitor the overall time spent on information collection and analysis, with regards to time spent on direct rehabilitation activities with clients

9. Establish systems for the reporting of monitoring and evaluation outcomes
- Identify who will be responsible for preparing reports based on monitoring and evaluation activities and outcomes
- Ensure there is clarity of roles, e.g. who will be responsible for preparing which reports, for which audience (such as management, practitioners, clients, donors)
- Ensure that management has a clear system for monitoring the timeliness and the quality of reports on monitoring and evaluation activities and the appropriateness of reports for each audience
- Ensure reports relate to the goals and standards set by the organisation, and that they provide management with clear direction on where the gaps are, where improvements are needed (in services as well as on data recording, data collection, monitoring and evaluation tools used, method of analysis etc.), and areas of good practice to guide future planning and service development

10. Establish systems for appraising monitoring and evaluation reports to identify organisational priorities for improvement and to identify innovations and good practice
- Agree organisational protocol on how and when monitoring and evaluation reports are disseminated to all everyone in the organisation, from management to staff at all levels.

- Establish a system for appraising monitoring and evaluation reports (e.g. by the relevant task force/committee/team, by management) to identify organisational priorities for improvement. This requires that those reading and appraising the reports must together have relevant skills (e.g. skills in conducting and appraising qualitative and quantitative data analyses, skills in interpreting analyses presented in reports); and knowledge (e.g. understanding service systems and protocols, understanding methods of data analysis, knowledge of professional regulation and standards and changes)

11. Establish systems to identify and respond to actions required from management, practitioners, administrators and others for continuous improvement and for future planning of service development

- Establish a system to identify which actions are required by management, staff and others to address gaps, areas for improvements identified in monitoring and evaluation reports
- Establish a time-frame for when the improvements required are carried out and by whom
- Establish how progress on actions will be monitored by management

12. Establish systems to identify and disseminate good practice
- Establish how good practice and innovations can be easily identified within monitoring and evaluation reports
- Establish how good practice and innovations are disseminated, so that there is positive feedback and organisational learning to embed good practice across rehabilitation services within the organisation

13. Establish systems to monitor risks to quality care, internally from within the organisation or from the external environment and context
- Establish how risks to quality care within the services are to be easily identifiable within monitoring and evaluation reports
- Establish a system to monitor any organisational developments or changes which create a risk to the quality of care and services provided; and to identify actions required
- Establish a system to monitor any changes or developments in the external environment (e.g. armed conflict, humanitarian crises, funding changes, changes in state service provision) which do/may create a risk to the quality of care and services provided within the organisation; and to identify actions required

14. Establish systems to respond to risks to quality care and to changes in the internal or external environment of organisations which impact on service provision
- Establish a system to respond to changes in legislation (national and international), with clear lines of accountability and clarity in roles and responsibilities across the organisation
- Establish a system to respond to changes in professional regulation and/or guidance from professional bodies, expert good practice guidelines, clinical guidelines and advancements in knowledge and practice, as relevant to service provision and quality of care

15. Establish systems to monitor resources used and required for effective monitoring and evaluation
- Regularly review organisational resources used, required and allocated to conduct appropriate and effective monitoring and evaluation
- Plan for future training for competency-building within the organisation, across all levels of the organisation, to ensure effective monitoring and evaluation practices

- Plan for future resources required, taking into consideration the necessary quantum of staff time, and the specialist experience, knowledge and skills required to ensure effective monitoring and evaluation

16. Ensure that management and the Board (where relevant) have appropriate background and leadership capacity
- Ensure that the organisation has effective management and leadership to ensure monitoring and evaluation systems are appropriate for rehabilitation services for torture survivors, and effective in ensuring continuous quality improvement
- Ensure that management collectively has relevant knowledge and skills to understand monitoring an evaluation reports and their implications

17. Monitor the above periodically
- Ensure that management periodically reviews these systems (e.g. minimum every 2 years) and makes necessary changes to improve the governance of monitoring and evaluation of rehabilitation services provided.
- An important consideration is the time and resources necessary to conduct effective monitoring and evaluation, with a system that works for the organisation

4.3 Design considerations

Important considerations in designing effective monitoring and evaluation systems include the service design, the resources available and stakeholders' requirements.

Service design

The first task in designing such systems is to be clear about the nature of the service. What is the service design, what is the service model and what are the service's/organisation's goals? Section 5 addresses this first stage in more detail.

Resources

The design of monitoring and evaluation systems would inevitably have to take into account resources available, but also to anticipate and to strategically plan for resources which would be required to improve and develop those systems. In smaller organisations which may also be new, the monitoring and evaluation systems may be modest, though should not be designed in a way that precludes further development as the organisation and services expand or develop. In larger and well-established organisations with many services, designing and implementing monitoring and evaluation systems where none previously existed is a significant undertaking and will require adequate resources. Whatever the size of the organisation, it is good practice to design monitoring and evaluation systems which meet current priorities within existing resource availability but which are designed with clarity on where they need to develop further, and with room for such development and improvement in the future.

Stakeholders

For a monitoring and evaluation system to be workable, it is essential that its design takes into consideration the needs of different stakeholders, especially clients. It is good practice to consult widely before designing such systems but also to review those systems periodically to ensure the systems developed are appropriate and acceptable to key stakeholders. The main questions are: Who are key stakeholders, and what are their needs and requirements? (See Box 3)

Box 3: Design Considerations in developing a monitoring and evaluation system: Needs of stakeholders

Clients' Needs

A system and methods which are:

- Acceptable and meaningful to clients
- Non-intrusive
- Respectful
- Based on informed consent
- Confidential
- Collaborative and seeking views of clients

Practitioners' Needs

A system which is:

- Easy to implement
- Acceptable to staff
- Not disruptive to therapeutic work
- Minimises client attrition
- Minimal bureaucracy
- Time-efficient
- Useful for clinical team decisions on client care
- Useful to develop and improve services
- Useful for strategic planning of services

Service Needs

A system which:

- Is secure, ethical and professional
- Tailored to the design of the service and its goals
- Addresses key questions relevant to international and professional standards for rehabilitation
- Addresses key questions relevant to the organisation's goals and services
- Provides general data and overview of quality of whole service
- Provides specific data and detail, where necessary, on particular aspects of services
- Identifies gaps, weaknesses and areas for improvement
- Informs strategic planning, improvement and development of services
- Meets requirements of donors
- Requires minimum administrative resources

Donors' Needs

A system which:

- Meets donor requirements for reporting
- Responds to donors' general and specific questions and concerns regarding service provision
- Provides easily accessible, clear information which is easy to interpret and to understand
- Identifies gaps, weaknesses and areas for improvement

4.4 Key principles in designing monitoring and evaluation systems

Each organisation will decide what their key priorities are in designing a system for measuring the quality of services, and their monitoring and evaluation systems may differ in some ways from those of other organisations, whilst sharing some commonalities. However, there are important guiding principles for the design of monitoring and evaluation systems for services for the rehabilitation of torture survivors. These are summarised in Box 4 below:

Box 4: Key principles in designing monitoring and evaluation systems

- **Client-centred:** All monitoring and evaluation systems, practices and activities should ensure the best interests of clients as the main priority. They should be respectful to clients, non-intrusive, non-burdensome and acknowledge the impact on clients. They should not hinder therapeutic contact with clients.
- **Ethical:** All monitoring and evaluation systems, methods, tools and practices should adhere to ethical principles, including the principles to do no harm; to protect torture survivors from avoidable harm, suffering or exploitation and from any breaches of confidentiality.
- **Competent:** Monitoring and evaluation systems and practices should be designed and implemented by those competent to do so, with appropriate knowledge and skills.
- **Accountability:** Monitoring and evaluation should be seen as a means to ensure accountability: to clients, to donors and to other stakeholders.
- **Meaningful:** Monitoring and evaluation should be meaningful to clients, relevant to their needs, to their experiences and their cultural backgrounds; and such that they make sense to them in light of the torture and other hardships and injustices they have experienced, or are still experiencing currently.
- **Respectful and enabling:** All monitoring and evaluation should be respectful to torture survivors and their families, and seek to enable them to participate in their rehabilitation, share their views and to provide feedback on services they receive, without adverse consequences.
- **Participation of all staff and management:** Monitoring and evaluation should be a collective task and a collective responsibility which engages all staff and all management
- **Involving torture survivors:** Monitoring and evaluation systems and practices should consult torture survivors on their views on those systems and practices and ways to improve them. Torture survivors must not be seen as passive recipients of monitoring and evaluation activities and measurements which are 'done to them', but as active participants whose views and experiences of the organisation's systems and practices, including on monitoring and evaluation practices, are crucial to developing ethical, respectful and meaningful systems.

- **Professional integrity in the process of monitoring, evaluating and reporting:** The process of conducting monitoring, evaluation and reporting is one which is vulnerable to ethical and professional breaches which must be avoided and professional and academic integrity maintained throughout.

4.5 Summary

The task of establishing monitoring and evaluation systems and practices within an organisation is time-consuming, complex and labour-intensive. First, it requires that management and staff are clear about the benefits and purposes of monitoring and evaluation, as summarised in Figure 1.

Figure 1. Key purposes of monitoring and evaluation: management responsibilities

The process to establish a system from scratch may take at least one year, particularly for organisations which are severely under-resourced and overwhelmed with work and client needs. There are a number of steps management can take to ensure sustainable structures and systems as a foundation for effective monitoring and evaluation systems. These are summarised in Figures 2 and 3.

Step 1
- Establish governance structure (committee/working group)

Step 2
- Establish key management responsibilities (see steps in section 4.2)

Step 3
- Establish needs of stakeholders in developing a monitoring and evaluation system
- Ask torture survivors, practitioners, management, donors and other stakeholders what they need (Box 3)

Step 4
- Ensure key principles in designing monitoring and evaluation systems (Box 4) are addressed

Figure 2: Key steps in establishing monitoring and evaluation systems
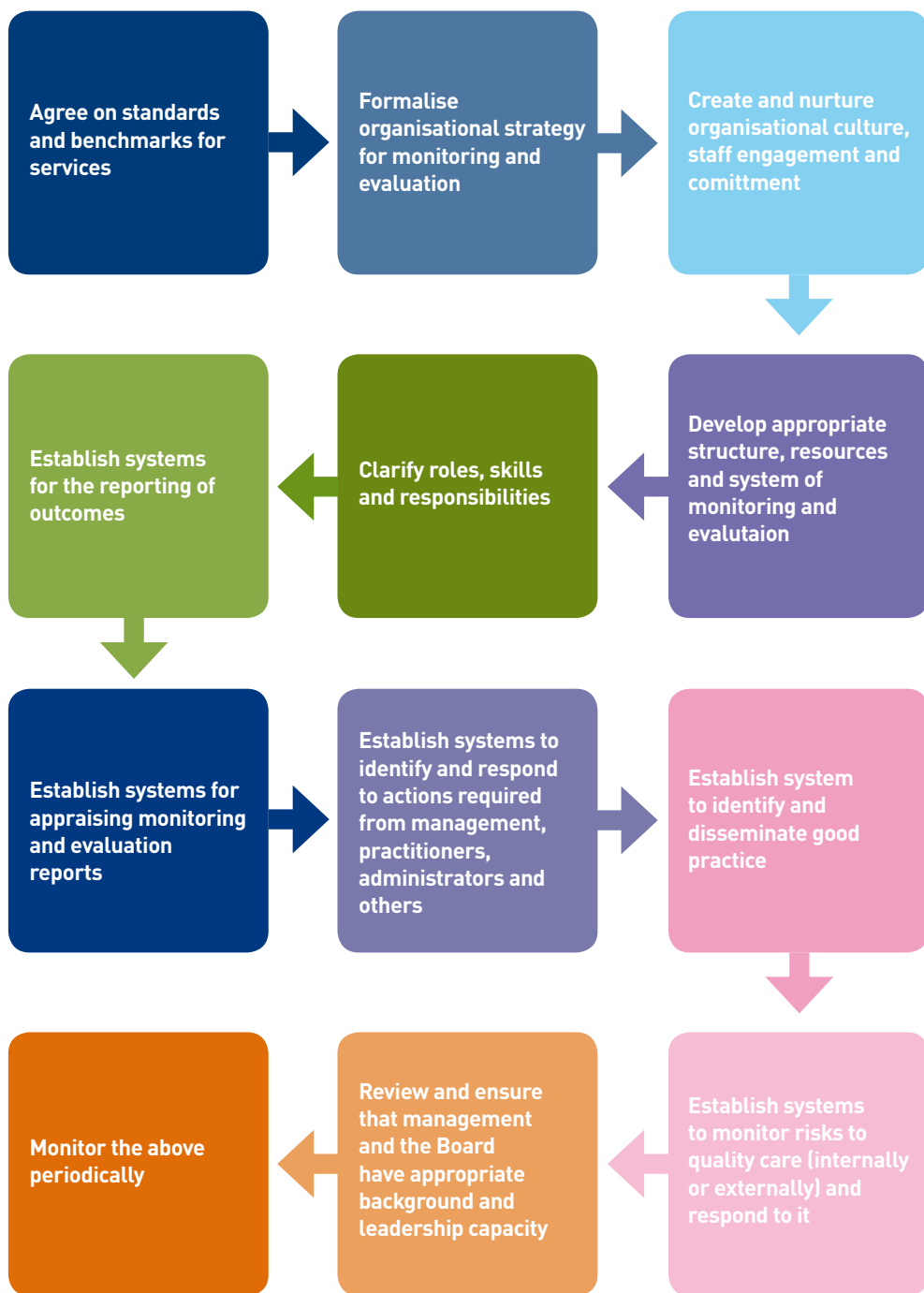
Figure 3: Management responsibilities in ensuring effective systems for monitoring and evaluation

The flowchart contains the following boxes connected by arrows:

- Agree on standards and benchmarks for services
- Formalise organisational strategy for monitoring and evaluation
- Create and nurture organisational culture, staff engagement and comittment
- Develop appropriate structure, resources and system of monitoring and evalutaion
- Clarify roles, skills and responsibilities
- Establish systems for the reporting of outcomes
- Establish systems for appraising monitoring and evaluation reports
- Establish systems to identify and respond to actions required from management, practitioners, administrators and others
- Establish system to identify and disseminate good practice
- Establish systems to monitor risks to quality care (internally or externally) and respond to it
- Review and ensure that management and the Board have appropriate background and leadership capacity
- Monitor the above periodically

5. Design of rehabilitation services

The design of a service refers to the way in which the services are structured and delivered to meet the aims of the service and organisation. This section first addresses why service designs are important to developing appropriate monitoring and evaluation methods, before addressing the range of factors relevant to service design. Finally, a sample of common service models is presented, with their key features and implications for monitoring and evaluation.

5.1 Why is it important to understand the design of a service?

The design of a rehabilitation service encapsulates the philosophy, values and goals of an organisation. To ascertain if the service is meeting its goals, and to an appropriate standard, the aim of monitoring and evaluation, it is important to recognise what the service sets out to do and what the identified needs of its client population are.

It is also important to recognise that there is a diversity of service designs, context, setting and other factors which shape any particular service. Each design will have certain implications for how monitoring and evaluation systems are developed, and which methods are likely to be useful and appropriate for that particular service.

5.2 Are all rehabilitation services the same?

All rehabilitation services are not the same. There are, however, many similarities also across rehabilitation service designs. It is important that donors and service providers do not assume that there is only one way to monitor and evaluate a rehabilitation service for torture survivors. Each monitoring and evaluation system will depend on the overall service design, and the service remit, goals and context.

In international law, the UNCAT's General Comment 31 defines rehabilitation for torture survivors as "medical, physical and psychological rehabilitative services; re-integrative and social services; family-oriented assistance and services; vocational training, education etc."
The "etc." implies that rehabilitation can be seen as possibly wider than those services listed, though these services are recognised in the field as core services. Hence, rehabilitation is often used as an umbrella term for the design of different services, which vary in their components, emphasis, combination and delivery.

5.3 What factors influence a service design?

Many factors shape the design of a rehabilitation service, with implications for monitoring and evaluation. The variations in the design of rehabilitation services depend often on the local and country context, client population and needs, the service model, the philosophy and theoretical models of the organisation. Changing political, economic and social context can also influence the design of services, as can the availability of appropriately qualified professionals. Funding availability, the sources of funds and restrictions (e.g. if funds are for specific projects), can also influence service design.

Context

Rehabilitation services may be very specific to each country context, for example, offering services to nationals of that country who have experienced torture by the current or previous regime, as well

as torture survivors who are asylum seekers and refugees. Other services may be designed to work with torture survivors living in refugee camps, who have fled conflict and torture in a neighbouring country, recently, or some years previously. Some services may be designed exclusively to work with torture survivors who are asylum seekers, or exclusively those with refugee status. Some services are designed according to psychiatric diagnoses, offering services only to those torture survivors who meet the diagnostic threshold for post-traumatic stress disorder.

Client needs

Rehabilitation services are best designed to meet the needs of torture survivors. It may be that services differ in their emphasis, and focus on some needs to the exclusion of others, or focusing on all needs clients present with. For example, some services only offer psychological treatment predominantly for post-trauma stress. Others may offer services which are psychological and medical, but the medical services may be limited to assessment and referring on to more specialist services in state health facilities. Some services may view integration or re-integration into society and resuming some sense of belonging, purpose and function in everyday life as a key component of rehabilitation and therefore these services may offer vocational and educational guidance, skills-building training, community-based activities etc. Some offer a range of services to meet a range of needs presented by torture survivors, all in the same organisation, such as psychological, medical, social welfare, legal, educational and vocational support, others focus only on one or two main services to address some of the commonest health needs only presented by torture survivors.

Theoretical models

The theoretical models preferred by the organisation very much influence the design of rehabilitation services. These models can differ quite considerably, for reasons which are complex and beyond the scope of these guidelines. Related reasons include the professional backgrounds and the theoretical preferences of clinicians and those in senior clinical roles, which can shape the emphasis of a rehabilitation organisation and define the service design and services offered. Other reasons include the historical dominance of certain theoretical schools, models and approaches within any national context. Finally, some theoretical models may be privileged in some service designs by related funding incentives, for example, when the use of particular methods within a service is supported by funding by external bodies or researchers testing and/or promoting their models and methods.

Philosophy

The philosophical underpinnings of most services offering rehabilitation to torture survivors relate, in some way, to the aspiration to provide healthcare to those survivors in need. How healthcare and need are defined and prioritised in the service criteria vary. Further, some services are explicitly healthcare-focused, and others promote principles of human rights and use international human rights as the basis of their philosophical approach. In short, the philosophy of a rehabilitation service is most often exemplified in their mission statement. This defines the design of services, which services are fore-grounded, which are offered and which are excluded. The philosophy also shapes the design of how and where services will be delivered – in one building or centre, in the community, in schools, in refugee camps, in detention centres, in state-run healthcare facilities etc.

Goals of services

The goals of a service are an integral aspect of service design. They articulate the service philosophy, elaborate on the mission statement, and give clear indication of what the service is

designed to do. In other words, the goals of a service define its primary task(s).

Monitoring and evaluation systems cannot be designed effectively or meaningfully if the goals of the organisation are not clear. It can be helpful to have goals which are achievable, specific and measurable. For example, S.M.A.R.T criteria may be useful in defining goals: Specific, Measurable, Attainable, Relevant, Time-bound.

Examples of SMART goals for rehabilitation services for torture may be:

Early identification: All refugees in the refugee camps will be assessed systematically, within one month of arrival in the camp, by trained health professionals to identify torture survivors and to refer them within 2 days for further, specialist assessment in the torture rehabilitation centre.

Specialist, multidisciplinary assessment: All those referred for assessment will receive a multidisciplinary assessment of their holistic needs and experiences of torture within 3 weeks of the referral being received.

Holistic rehabilitation services: Torture survivors will be offered individually-tailored services, with an intervention plan, based on their needs, within 2 weeks of the initial specialist multidisciplinary assessment being completed.

Standards of care: All torture survivors will receive services which meet the highest standards of care, provided by appropriately qualified and supervised staff, acting within ethical and professional standards of their profession, and within the code of conduct of the organisation.

Confidentiality: All client records containing personally identifiable information, including personal data, experiences of torture etc. will be (a) secured in locked cupboards and locked and secured premises, without access by anyone except those involved in the direct care of that client; (b) disclosed to no one, without the explicit consent of the client, except where there is a legal duty to do so, such as when there is a risk of suicide, harm to self or others or child protection concerns.

Informed consent: All clients will be informed fully as possible, prior to services and intervention plans being implemented, of the intervention plan, the nature of the interventions offered to them, their limitations and any anticipated or possible adverse consequences for them or family members. A record of informed consent shall be obtained using the consent form, and filed in the client's file.

Review of intervention plan: All clients' intervention plans will be reviewed, in discussion with clients, and with all staff involved in their rehabilitation, regularly, and both a record of this review and a revised intervention plan, as necessary, will be stored in the client file. The review will include consideration of (a) the appropriateness of the interventions according to the client's needs, context and culture, as defined in the previous assessment, and according to the former intervention plan; and (b) the impact of interventions provided for the client and family (where relevant)

Monitoring: All activities and services provided by the organisation to promote the rehabilitation of torture survivors will be monitored regularly, and analysed and reported upon annually.

Evaluation: All activities and services provided to promote the rehabilitation of torture survivors will be evaluated routinely for each client, and outcomes and the impact of overall rehabilitation

will be assessed and documented in the client file, at a minimum 6-month intervals during service provision, and at the point of discharge, by the key-worker or a nominated clinician for the client or family.

5.4 What is a service model?

Service models operationalise the organisation's overall design: the organisation's philosophy, mission statement, key goals, local context and client needs. Part of the context which influences service models include funding availability, and restrictions, on what can be offered, to whom, in what settings, how. In summary, service models define how services are structured, and operationalised, and delivered.

The service model adopted is one of the most significant factors to take into account in designing monitoring and evaluation systems since, to address questions of whether the service has any impact and if it is effective in achieving its goals, it is essential to define what the service model is and what it aims to do (and what it does not).

5.5 What are common service components?

Rehabilitation services will comprise a range of components, each organisation varying in what services they offer. Rehabilitation components may be offered singly, in combination, sequentially (e.g. two or more services following one another) or simultaneously (e.g. several services offered at the same time). Rehabilitation components may include:

- Psychological, medical, social, legal, welfare, educational, vocational, integration services, for:
- Children, young people, adults, couples, families, communities
- Assessment/examination for documentation of torture and of its impact
- Assessment/examination for treatment and care
- Interventions (individual/group/families/communities; medical/physical, psychological, social, welfare, housing, legal, educational, vocational guidance, livelihood-building; early or crisis interventions, medium-long-term interventions)
- Advocacy (e.g. for individuals, families)
- Prevention activities (e.g. awareness-raising, advocacy to influence policy, litigation, using national mechanisms, UN complaints mechanisms, regional or other international procedures)
- Capacity-building (e.g. of health and social care professionals in State facilities and in NGOs, legal representatives)
- Education (e.g. for students training in medicine, clinical psychology, physiotherapy, nursing, social work, human rights law etc.)

5.6 What is the nature of service delivery?

Services can be delivered in a range of settings to a range of people. Questions to clarify in developing relevant monitoring and evaluation systems are summarised in Box 5.

Box 5: Key questions regarding service delivery

- **Where are the services delivered:** in the centre, in mobile clinics, satellite centres, state facilities, detention centres, schools, in clients' homes, community centres, places of religious worship etc.? Why?
- **How far are services spread:** in one or more cities, only in the capital, in rural and urban areas nationally, in refugee camps? Why?
- **How are services delivered:** by teams, by individual practitioners,
- **How long are services available:** as long as client/family needs persist, time-limited – and what are the criteria and justifications?
- **By whom:** medical doctors, physiotherapists, complementary therapists, clinical psychologists, psychiatrists, social workers, caseworkers, welfare advisors, lawyers etc.? With staff from other agencies, jointly, or independently by staff in the rehabilitation service only? By volunteers, by paid staff, by appropriately qualified professionals, by lay persons with basic training? Why?
- **When:** early intervention, primary care, secondary care, tertiary care, pre-resettlement, post-settlement, pre-removal or deportation from country where asylum sought?

5.7 What are common rehabilitation service models?

As stated earlier, in order to design appropriate monitoring and evaluation systems, it is important to specify and fully understand the overall service design, the specific service model adopted, and its goals. Examples of service models are presented below, though there exist many variations of these models, each with their strengths, merits and limitations

Service Model 1: Independent specialist centre

This service model typically offers rehabilitation services only within the independent centre by staff specialising in working with torture survivors and their families.

Geography and location: Such a service often would be located in an independent office/building in a main city, taking referrals from the local area or nationally (from State health services, other NGOs, legal representatives of torture survivors and self-referral).

Staff: Staff may be predominantly from one profession (e.g. medicine, clinical psychology, counselling) and hence influenced and led by particular models dominant within any one profession (e.g. some services may be dominated by the medical model of healthcare, others may be more psychological, some adopting a more generic psychosocial focus). In some specialist centres services, staff may be from a range of backgrounds, in equal proportion and multidisciplinary, some with formal professional health and social care training, some with other training or work experience. Staff may be paid or volunteers, part-time or full-time.

Services often include:
- Medical and psychological assessment and documentation of torture
- Assessment, guidance and/or sign-posting or inter-agency referral to other state health/NGO services
- Individual psychosocial support/therapy
- Family support
- Social welfare advice and support
- Legal support and liaison with legal services
- Referrals taken and received from various agencies, including State services, NGOs etc.
- Capacity-building efforts may be directed at State services.

Funding: The model of funding in such centres tends to be independent of the State, with some relying on State funding for specific capacity-building projects or training initiatives. Service provision may depend on funding availability specifically for particular services or projects, such that service components may change subject to funding.

Service Model 2: Independent Specialist Centre and Satellites

This service model is very similar to service model 1, with the main difference being that the main centre is supported by additional satellite centres, in other locations nationally. The emphasis of such satellite centres may be balanced more in favour of capacity-building than direct service delivery, to meet local needs and to address limited staff resources nationally. Capacity-building may be directed at State services and other agencies working with torture survivors. Satellite centres may refer to the main specialist centre for specialist services not always available in the satellite centres nationally. Specialist centres may refer to other agencies, including NGOs and community organisations, and some may take referrals from those agencies too. Survivors may refer themselves directly to those agencies, and in some services they may be able to self-refer to the specialist centre or its satellite centres.
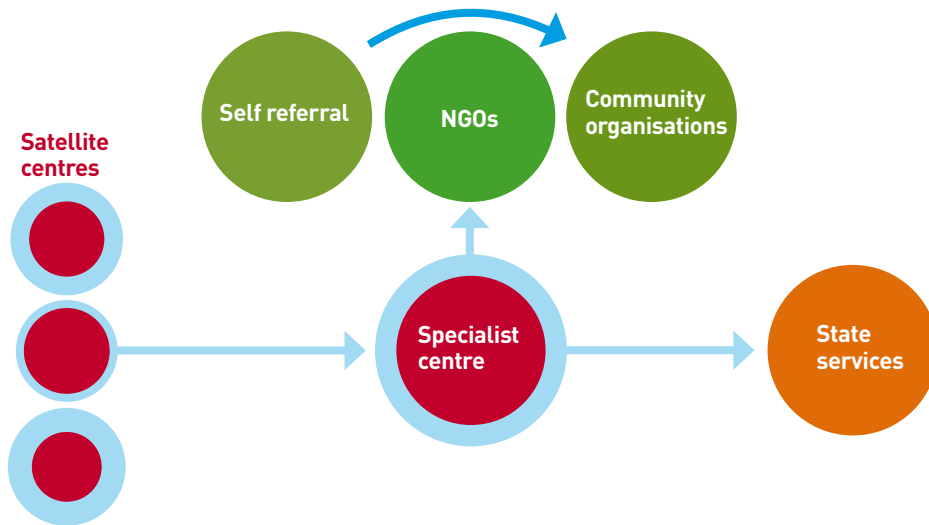
Service Model 3: Specialist team within mainstream services (state).

This service model offers rehabilitation services within a specialist team (not a specialist centre) which is part of State-provided services. The specialist team may be defined as specifically for clients who meet specific criteria such as 'refugees and asylum seekers', or 'trauma centre', or 'post-traumatic stress disorder clinic'. It is extremely rare to find a specialist torture rehabilitation service within State services. The specialist team may take from and send referrals to other State health and social care services, acting as a bridge or focal point for survivors requiring different services. A variation of Service Models 1, 2 and 3 may be a hybrid service where some services are provided by an independent centre specialising in torture rehabilitation, located separately and some services may be offered jointly with State services.
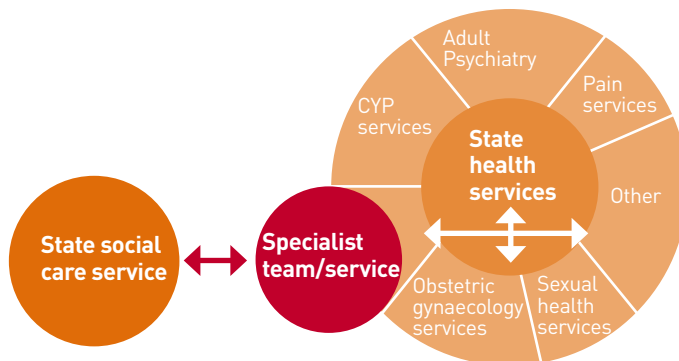
Geography and location: Such a service may be positioned structurally within a hospital or health department, and located usually within a general or specialist hospital setting, or an adjunct building. Referrals may be made to and received from other State health and social care services, either from the local health service, the local area, or nationally.

Staff: Staff may be predominantly from one profession or multidisciplinary; specialising in one area of health or social care (e.g. post-trauma stress); or with a particular client group (e.g. children, adults, refugees). Staff are usually State services employees.

Services can include:
- Medical assessment (but not necessarily documentation of torture)
- Psychological assessment (but not necessarily documentation of torture)
- Assessment, guidance and/or sign-posting or inter-agency referral to other State health/NGO services
- Medical interventions
- Physical and complementary health services
- Individual psychological support/therapy
- Family support/therapy
- Social welfare advice and support (but not legal advice or support)

Funding: The model of funding in service models is often State-dependent. Service provision may depend on funding availability and priorities of the State, and/or service commissioners and managers. Hence, service components may change, according to funding priorities and depending on State health policy and priorities, all with implications for service monitoring and evaluation.

Service Model 4: Specialist team in NGO

Service Model 4 delivers rehabilitation services within a specialist team which is part of an NGO or INGO whose remit is wider than, and not specific to, torture or rehabilitation for torture survivors. The specialist team may be specifically for particular groups of people, defined perhaps as 'survivors of torture', or 'survivors of war trauma'. The services are provided independently of other NGOs specialising in torture rehabilitation, and independently of State services.

Geography and location: Such a service may be located within a centre, or within more than one centre or satellite of the NGO's main local location. Referrals may be made to other NGOs or other State health and social care services. Referrals may, in some cases, be received from outside the NGO, but often referrals are initiated where survivors and their needs become more apparent via the other core activities of the organisation.

Staff: Staff may be predominantly from one profession or multidisciplinary; often from a limited number of disciplinary backgrounds (e.g. medicine, psychiatry, psychology); and services may

be only for adults or only for children. Staff are usually paid employees. In some service models, the staff are a mixture of local professionals, and those from other countries, considered as 'international experts'. In some cases services are provided mainly by 'international' staff.

Services can include:
- Medical assessment (but not necessarily documentation of torture)
- Psychological assessment (but not necessarily documentation of torture)
- Individual psychological support/therapy
- Social welfare advice and support
- Legal advice or support

Funding: The model of funding in Service Model 4 depends on a range of funding sources, with service provision and sustainability dependent on funding availability and priorities of the NGO. Service components may change, according to funding availability and organisational priorities, with implications for service monitoring and evaluation.

Service Model 5: Community specialist centre

Service Model 5 is a hybrid model, with a specialist, independent centre/team offering core services for complex cases; alongside community-development, working within and with local communities; and ongoing capacity-building for mainstream state health services and for other NGOs.

Capacity-building
- Network-building
- Competency-building
- Establishing referral pathways
- Transitional support services

Service-development
Core team/centre providing support to other organisations nationally and developing other rehabilitation servises in different regions nationally

NGO 1

State services

Specialist team/centre

NGO 2

NGO 3

Community development
- Community outreach and organisation
- Prevention & awareness-raising
- Facilitating access to services

Awareness-raising & advocacy
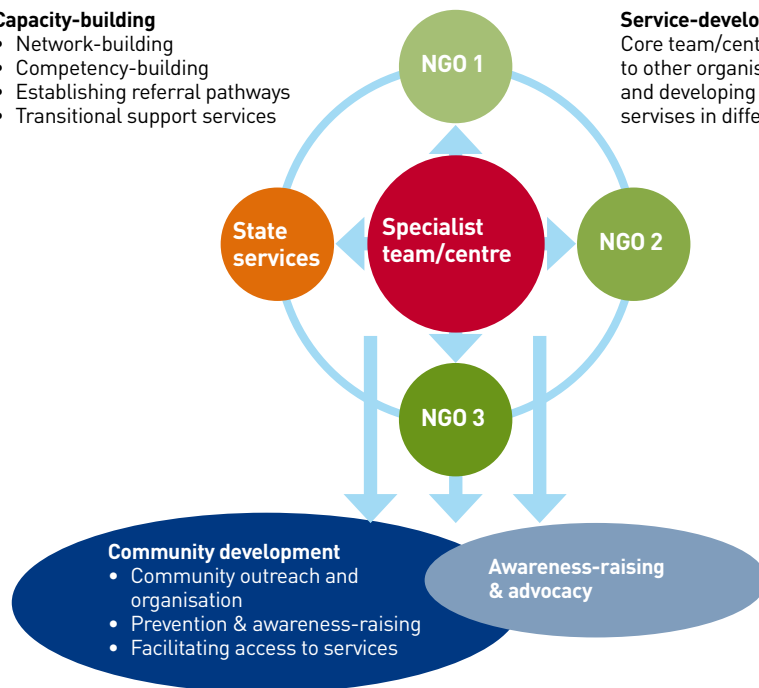
Geography and location: This service model may mean that the core specialist team or centre is located in one or more geographical locations, rural or urban, typically within the community or within existing community-based health services, rather than as a stand-alone centre or within a larger NGO. The service model may include satellite centres and/or mobile teams, located within communities (including refugee camps) wherever torture survivors are most concentrated.

Referrals may be taken directly from the community, either by self-referral or referral by the organisation's community workers, from other state health and social care services and from other NGOs.

Staff: Staff may be a combination of specialists in health and social care, legal advice and community workers with diverse backgrounds. Staff may be paid or volunteers.

Services and activities can include:
- Initial assessment/screening to identify torture survivors and those most vulnerable
- Early intervention
- Signposting/referral to other agencies
- Medical assessment and documentation of torture
- Psychological assessment and documentation of torture
- Individual psychological support/therapy
- Social welfare advice and support
- Legal advice or support
- Capacity and competency-building: advice, clinical consultation to colleagues in other health services, clinical supervision, training to others etc.
- Prevention: community engagement, awareness-raising, facilitating individual access to redress and rehabilitation services within the specialist centre/state services
- Prevention: Facilitating access to redress (e.g. referral to other agencies, including those specialising in legal redress)

Funding may depend on a range of sources. Service components and focus may change, according to funding availability, organisational priorities and changing context and communities where torture survivors reside (e.g. in specific communities, refugee camps etc.). This would then have implications for service monitoring and evaluation systems, as both context and funding priorities change.

5.8 Summary

The design of rehabilitation services encompasses the philosophy, values and overall goals of an organisation. The design of services is often responsive to a range of factors, including client needs, local context and funding. The service model developed by each organisation operationalises the service design, and determines which services are offered, to whom, how, where and when. To develop meaningful monitoring and evaluation systems it is essential to understand the service model and its goals. Key steps in clarifying service models are summarised in figure 4.

Step 1
Ensure
- **The organisational philosophy and core values are clear**

Step 2
Ensure
- **The service model is defined**

Step 3
Ensure
- **The service components are defined**
- **The way services fit together and how they are delivered is clear**

Step 4
Ensure
- **The service has stated goals, linked to quality standards**
- **The service goals are clearly articulated and measureable and which may be short-term or long-term**

Figure 4: Summary of key steps in designing monitoring and evaluation systems for the organisation

6. Monitoring of rehabilitation services

This section addresses monitoring and the different purposes and approaches to monitoring of rehabilitation services for torture survivors. Methods and the challenges involved in conducting monitoring are outlined. Examples of clinical audit projects are provided to illustrate how services can be monitored against quality criteria and established standards towards improvement of those services.

6.1 Defining monitoring

Monitoring is defined as the ongoing measurement of activity conducted by a service or organisation. Monitoring addresses specific questions, summarised in Box 6.

<div style="background:#C8102E;color:white;padding:4px;font-weight:bold;">Box 6: Questions which monitoring addresses</div>

1. **Agreeing standards:** 'What are we trying to achieve?'
2. **Assessing:** 'What is happening currently?' 'Who are our clients?' 'What are their needs?' 'What is our current practice; what are we doing?'
3. **Comparing findings to standards:** 'How does what we do match up to what we say we should do and our organisational goals?'
4. **Identifying changes needed:** 'What should we be doing or what would we need to do in the future to improve?'
5. **Reviewing impact of changes implemented:** 'Did the changes we made make a difference? Are there any improvements?'

Monitoring typically focuses on outputs, and some outcomes:

- **Outputs** are the products, services or facilities that a project or service delivers to/or provides for service users
- **Outputs** are measured using output indicators. Output indicators help assess and measure the work generated by the project or service and show progress towards meeting stated outputs, or targets
- **Outcomes** may include changes assessed against targets such as progress of clients, measured in various ways, including by use of standardised routine clinical outcome measures

6.2 Types of monitoring

The term monitoring is often used loosely, and approached as a routine recording of information and the provision of a summary of such information when requested by others, for example, donors. Monitoring is however, much more than simply recording information and summarising it. Monitoring is a tool in ensuring quality services, in improving services and in planning and developing new services.

Different types of monitoring focus on different questions and can serve different purposes. For example:

- **Monitoring client population of a service:** addressing the questions of who and how many people are using a service, what is their health status, what are their rehabilitation needs, what are their torture experiences, what is their socioeconomic and legal status, what is their

country background, ethnicity, gender, age etc. This can involve identifying trends, patterns, changes in patterns, and analysis of possible reasons internally within the organisation, or reasons related to the external context. Such information can be very useful to demonstrate who service users are, their needs, experiences of torture, the types of services they access and duration of service use.

- **Monitoring human rights data:** addressing specific questions of the types of violations, types of torture, perpetrators, the circumstances of the violations and other information which may be relevant for monitoring trends in torture practices, perpetrators, target groups etc. Such monitoring can also help identify new human rights violations, new groups of survivors, and their experiences. This can help not just in planning services, but also to better understand human rights violations, and identify ways to use aggregated, anonymised data to prepare country reports, shadow reports for UN monitoring mechanisms, discussion papers and other documents for human rights advocacy.

Using routine data collection to identify particular instances of torture, or particular individual cases does not come under monitoring since it requires a breach of confidentiality in using personally identifying information. The risks to the safety and privacy of clients, and the complexity of such data monitoring, where data may not be anonymised, requires formal process of seeking ethical approval, beyond the scope of this publication.

- **Monitoring service use:** addressing questions of which services are used by which clients, for how long, how many clients drop out of rehabilitation services without a planned discharge, how many services (different service components) do clients with different needs or backgrounds use on average etc.; appropriateness (are services appropriate to the needs of the clients, are services acceptable to clients etc.?). Monitoring service use can also provide valuable information on how and which clients access which services, and their trajectories within the organisation as they are offered and use different services at different times, for different periods. Such overall monitoring can be crucial in planning future services and making strategic decisions about changing client needs and patterns in service utilisation.

Whilst such information, if recorded in each client record, can inform the care plan for each client, and guide decision-making, the purpose of monitoring is a broader activity which relies on anonymised data to identify trends across the client base, rather than look at individual trajectories.

- **Monitoring service delivery:** addressing questions, for example, of timeliness of a service (how prompt are services in early identification, assessment, offering therapeutic services, referring on etc.); and accessibility (are all services accessible to all clients, which services do certain groups of clients not use, are there any unexplained or unwarranted variations in service use by some client groups, are there any inequities in access to services); coherency (are all clients offered a multidisciplinary assessment, are all cases reviewed by a multidisciplinary team, is client care coordinated across professionals from assessment to discharge, is client care recorded in a common, multi-disciplinary client file, is there a record of all other agencies involved in the care of the client and the nature of the care offered by each etc.?).

Monitoring service delivery is an approach to assessing the quality of services against set standards. Again, this involves an approach which relies on anonymised and aggregated data. Aggregation can be, for example, according to particular variables (one or more) such as

gender, age, country background, torture experience, health problems, legal status etc.

- **Monitoring service standards (audits):** addressing questions such as are clinical records kept to the standards required by the organisation and in keeping with professional and ethical standards, are all clients informed of services available to them and which will be offered to them, before their consent is sought, are all client records securely kept and confidentiality assured, are torture experiences routinely and adequately assessed and documented according to international and professional standards etc.?

Monitoring specific service standards is often referred to as the audit process. In health services these may be referred to as clinical audits which are typically projects designed to measure how well a service meets specific standards. This requires each organisation to clarify their standards for the services provided in ways which are clear and measurable, for example, using S.M.A.R.T. criteria (specific, measurable, attainable, relevant and time-bound).

- **Monitoring a project-based service:** addressing questions of have the milestones of the service been met, what is the service usage, have targets for numbers of clients reached been met etc.

Monitoring projects within a service, or services funded specifically as a time-limited project (e.g. a music group-based service with young people aged 14-17), is a distinct activity, often within overall monitoring of all service provision in an organisation. Nevertheless, monitoring of a project involves following the progress of a project closely, against milestones set at the outset, within a specified time-frame determined by donors and the grant conditions, which may not match the time-frame for the organisation-wide monitoring of all services (e.g. which may take place only annually).

6.3 Monitoring as a cycle

Monitoring is not a one-off activity but an ongoing cyclical process for measuring what a service is doing in order to identify changes needed and to make improvements. Monitoring offers a unique opportunity to take a snapshot at any point in time, and ask 'how are we doing on this standard?' and 'what should we be doing to reach our standard?', followed by deciding and implementing action 'what changes should we make?', and a review of that action 'does this make any difference or make things better or worse and, if so, how?'. This process should inform further changes made to the monitoring method or tools, a refinement of the standard or benchmark, and/or a re-design of services, followed by another process of monitoring.

Monitoring requires engagement from staff across the organisation since all aspects of service delivery implicate more than one individual, team or service component, spanning administration, data entry, clinical staff and management.

What are we trying to achieve?

What are we doing currently? Are we achieving what we set out to achieve?

What needs to be changed/improved?

Implement change

Have these changes made a difference?

Figure 5. The routine monitoring and clinical audit cycle

6.4 Establishing a monitoring system

To develop an effective monitoring system, it is vital that various steps are taken by those with appropriate level of knowledge and skills and with appropriate leadership capacity and authority. Most monitoring systems and projects fail because of lack of resources, immense workload pressures, poor design, lack of a systematic approach to monitoring, lack of skills in monitoring methods, lack of understanding of quality of data, lack of follow-through, action and review following monitoring activities and lack of adequate leadership and management commitment to integrating monitoring and audit practices within the organisation.

Whilst establishing a monitoring system may be labour-intensive at the beginning, once set up the system can be adapted and developed over time based on what works, what works less well, and changing practices and needs of the organisation. It is good practice to develop a system which may be small in scale to begin with but which is workable and robust, and to develop it gradually, rather than a comprehensive system which is unwieldy and which cannot be implemented.

The key steps to developing a monitoring and audit system can be found in Box 6, and discussed in further detail in subsequent sections.

Box 6: Key steps in establishing a monitoring and audit system

1. **Allocating resources:** What resources do we need to first establish, to develop and maintain a monitoring and audit system?
2. **Agreeing roles and responsibilities:** Who will be responsible for what?
3. **Engaging all management and staff:** Who needs to be informed, engaged, how, when?
4. **Agreeing standards:** What are we trying to achieve?
5. **Deciding on types of monitoring:** What is needed by the organisation and why?
6. **Deciding the focus of monitoring:** What needs to be monitored and why? Which rehabilitation services, and which aspects, components etc.?
7. **Agreeing particular questions:** What needs to be asked of the information collected?
8. **Agreeing a minimum data set:** Which particular information is necessary to the organisation and why?
9. **Designing what needs to be monitored across the service or designing a specific audit project:** What do we need to know about our services and clients? What should we look at closely, how and with whom, in which area of the service?
10. **Designing data collection methods:** How will data be collected, by whom, where, when, how often and what period?
11. **Develop monitoring tools:** What do we need to ask, and how?
12. **Deciding data recording:** How will data be recorded, by whom, where? How should data recording be monitored?
13. **Deciding data collation:** How should all the data collected be gathered and collated? In what format? By whom? When/how often?
14. **Deciding data storage and retrieval:** How and where should data be stored, accessed by whom, how?
15. **Deciding data analysis:** How should data be analysed, by whom, when/how frequently?
16. **Interpretation of the analysis of information:** How should the analysis of data be interpreted, which methods, by whom? What does the data mean? How well is the service performing in relation to what we are trying to achieve (standard)?
17. **Deciding reporting:** How should analyses or findings be presented, in what format and detail for which audiences, by whom, when?
18. **Identifying change and action:** How will reports be reviewed and appraised, by whom, when? What needs to change to make improvements? Who will do what? How? Who will they report to?
19. **Implementation:** Make the changes agreed.
20. **Deciding review and follow-up:** By whom, how and when should the progress of action undertaken be reviewed to see if the action or changes implemented made any difference, and how? Should we repeat a particular audit project to review that service/practice, when, how? Do the relevant standards and indicators need to be better defined? Who should be consulted (colleagues, clients etc.)? Should the monitoring tools or methods be revised, how?
21. **Repeating:** Going back to the top: What are we trying to achieve?
22. **Agreeing indicators of successful monitoring and audit system:** is our monitoring system meeting our organisation's needs?

6.5 Allocating resources

To establish, develop and maintain an effective monitoring and audit system requires resources: time and appropriate expertise and skills and financial resources.

Establishing and implementing an effective monitoring and audit system is not a one-off activity. It takes time to establish but also for staff to fulfil their specific monitoring-related duties. Conducting monitoring and audit projects also requires considerable effort from practitioners and managers. It also takes time for relevant staff and management to meet to ensure the smooth implementation of monitoring activities for audit projects which are multi-professional, it can be difficult to find and protect time to meet, sometimes complicated by part-time working hours, or when staff are based in different locations and work with different schedules. Setting aside and protecting time to actually engage in audit activities is also important and cannot be squeezed into daily clinical time when staff may already feel extremely pressured. Ethical considerations will always be present and need to be discussed in each organisation – for example, when clients' needs are to be prioritised over other competing duties, including routine monitoring and evaluation activities.

It is also not a task which can be completed by one person, not only because it takes considerable time and effort but because it requires a range of knowledge and skills very rarely available in one individual. The most important areas of expertise needed include: systems design, managing clinical/health data and human rights data, ethical issues in monitoring, research methods, information and communications technology, database development, working within multidisciplinary settings, leadership in implementing monitoring systems and practices.

Often new or small organisations do not have the resources to conduct comprehensive monitoring and audit projects, and may be tempted to not do this at all, or to collect data unsystematically, which lacks integrity and coherence. Unfortunately, this can lead to superficial or shoddy attempts, however unintentional, which risk unsafe and unethical practices. It is the responsibility of management and all staff to ensure that monitoring and audit activities are not carried out at the cost of ethical practice with torture survivors, thereby compromising the care provided to clients, and undermining the integrity of reports to stakeholders and donors.

Routine monitoring and audit projects are also sometimes seen as an unwanted, unnecessary evil and as a chore to be completed only to meet donor requirements. It is the responsibility of management to ensure, by clarifying duties in contributing to monitoring and evaluation activities within job descriptions and by allocating resources, that staff value monitoring and evaluation not as a donor-driven chore but as good practice in providing professional, ethical, quality services to torture survivors and their families.

Financial resources are also necessary for information technology and this has to be factored in and allocated at the outset. Information technology is essential to monitoring and audit activities, for example, by providing appropriate data capture systems for client-related and service-related information.

Key questions:
- What expertise do we need?
- What are key tasks and duties of all staff and managers in relation to monitoring and audit projects?
- What resources do we need to first establish a monitoring system (for human resources,

database development etc.)?

- What resources do we need to pilot, further refine and develop continually our monitoring system?
- What resources are required to regularly design and implement audit projects, to monitor and to improve various aspects of our services?
- What resources are required to act on findings and to integrate changes indicated by our monitoring system and audit projects into the organisation?
- What resources are needed to ensure staff have relevant training on monitoring and develop skills in engaging in audit projects? Should such training be continuous, or one-off? Should support, advice (e.g. on use of monitoring data forms, using computerised systems for data recording, for clinical audit methods) and supervision on monitoring and audit activities be ongoing?

Good practice includes:
- Identifying the knowledge, skills and experience needed to conduct effective monitoring and audit projects in the organisation.
- Ensuring that staff are fairly remunerated according to knowledge, experience and skills required
- Ensuring staff allocate time to fulfil their duties in relation to monitoring and audits
- Identifying the information technology resources required, for necessary expertise and to build the necessary infrastructure and databases to capture information necessary for monitoring, audits and evaluation.
- Monitoring how ethical considerations and breaches are addressed in monitoring methods and practices
- Ensuring that client care is not compromised to fulfil monitoring obligations

6.6 Agreeing roles and responsibilities

Having identified resources required, organisations must be clear in agreeing the roles and responsibilities of staff and management to ensure an effective monitoring system and audit projects.

Sometimes when other work demands increase, monitoring practices and responsibilities may be neglected and suffer, perhaps where they are seen as burdensome bureaucracy and a management tool, rather than as a professional and ethical responsibility. Accountability in relation to monitoring-related duties is important to monitor and review periodically, usually by line managers. It is good practice to conduct reviews in ways that are not overly critical and punitive but which provide positive and constructive feedback, support and encouragement to staff, and which instil a commitment to providing professional, ethical and quality services to clients.

Key questions:
- Who will be responsible for what?
- To whom will they be accountable?
- How will accountability be monitored?

Good practice includes:
- Identifying what the tasks and duties are for practitioners, managers, administrative and other staff in relation to monitoring and audit activities
- Agreeing roles and responsibilities for all staff in relation to monitoring and audit activities, specified in their job descriptions

- Establishing methods to ensure accountability
- Monitoring how staff are fulfilling their duties in relation to monitoring, audits and evaluation, in management supervision and annual staff development reviews
- Providing feedback, encourage and support staff in fulfilling their monitoring-related duties

6.7 Engaging management and staff

As noted earlier, to establish, develop and maintain effective monitoring systems requires an organisation-wide effort, commitment, engagement and collaboration. All staff and managers need to be working together in the same direction, towards the organisation's and service's goals.

Monitoring and audit projects can be demotivating as they may highlight gaps or difficulties in services and practices. It is helpful if staff can be regularly reminded that 'pulling together' is about combining efforts to, first and foremost, improve services for clients, and this requires everyone's contributions and support.

Practitioners may feel overly scrutinised, and complain that monitoring processes feel like 'Big Brother is watching', or that the process feels bureaucratic, a 'numbers game' or 'watching the scoreboard and not the game'. Practitioners may feel that monitoring activities and duties detract from 'the real work' of clinical or rehabilitation activities. This is particularly serious, when monitoring activities are seen to, or actually do interfere with client care. Managers may need to make decisions, in discussion with practitioners, about how to modify monitoring requirements. Sometimes practitioners may complain that monitoring is a donor-driven requirement which they view as 'nothing to do with providing care to torture survivors'. Competition and conflict between teams or between professional disciplines offering different services can also manifest as resistance to monitoring and audit, sometimes for fear of being scrutinised, criticised and compared unfavourably to other services or colleagues within the same organisation. All these concerns need to be explored, discussed and addressed.

Practitioners may fear that the quality of their individual work and practice may be exposed to other colleagues or managers and that any negative findings from monitoring and audit activities may be attributed to them alone, rather than to practices within a team or service, and that they may be penalised or suffer adverse consequences in their employment. This might lead to certain standards not being chosen for auditing by a service, or resistance to monitoring certain standards, for fear that they may give rise to serious concerns about quality – such as timeliness of assessment appointments from the point of referral.

On the other hand, practitioners may feel as though they are part of an organisation-wide effort to provide the best care they can to torture survivors. Positive feedback, highlighting good practice and providing outcomes of audit projects promptly and in accessible ways can encourage all staff to be more engaged and committed to monitoring processes.

Managers also need to make efforts to understand the demands monitoring and audit projects make on staff, and the complications and difficulties which arise, for example in data collection, or data recording, or using computerised systems for data entry. Managers also need to understand where monitoring demands impact adversely on service delivery, and where they highlight gaps in knowledge, skills and particular expertise necessary for monitoring and audit activities.

Monitoring and audit activities are most effective when managers are all firmly committed to the process; they demonstrate their interest in and commitment to the quality of services; devote

time and energy for this process; and provide feedback to staff based on findings from monitoring and audit projects. Monitoring and audit activities are also most effective when they do not compromise service provision and direct client care.

Key questions:
- How can staff across all levels of the organisation and services be motivated and engaged in monitoring and audit activities?
- What can managers do to facilitate motivation, commitment and team-working towards organisation monitoring?

Good practice includes:
- Providing regular and prompt feedback (e.g. summaries of findings, presentations) from monitoring and audit activities, to all staff
- Highlighting and congratulating good practice
- Managers to taking time to demonstrate their interest in services, in service provision and in difficulties which arise for their staff in their daily work, in relation to monitoring and audit activities
- Reassuring staff that monitoring and audit activities are not a management tool to evaluate individual performance and to penalise staff but aim to identify areas for improvements in the service – the responsibility of all, not any one individual
- Reassuring staff that monitoring and audit activities are not about 'number crunching' and 'just counting numbers', but an ongoing process to improve quality, in many dimensions, which requires their cooperation and contributions to better understand services, their strengths, shortcomings and gaps

6.8 Standards and benchmarks

All monitoring activities and audit projects require clarity on the goals of a service, its standards and service model (see Section 4 and 5). Agreeing organisational standards for rehabilitation services for torture survivors relies on a process of interdisciplinary, inter- and intra-team, inter- and intra-service and inter- and intra-departmental discussion and understanding of each other's priorities.

For specific audit projects, where particular aspects of services, or practices, are being monitored, the standards must be clear and understandable to all.

Key questions:
- What are we trying to achieve in our services?
- Are the standards and indicators all comparable across teams or services, or are some standards to be defined differently for particular teams, or client groups (e.g. services for children)?

Good practice includes:
- Developing a process across the organisation, including all relevant staff and managers, to agree standards of quality services for the organisation
- Establishing a process for agreeing standards which are a priority for organisational monitoring and for audit projects
- Ensuring all standards for audit projects are clear and measurable

6.9 Deciding on monitoring approach

As described in section 6.2, there are different types of monitoring. These include monitoring the client population of a service; monitoring human rights data; monitoring service use by different client groups; monitoring service delivery according to agreed standards; and monitoring specific service standards by conducting focused audit projects; monitoring a project-based service to establish if agreed targets and milestones have been reached and how well the project is progressing.

Not all organisations will be able to conduct all types of monitoring, and the monitoring approaches decided will depend on what is prioritised by the organisation.

Key question:
- What approach (types) to monitoring is required for the service design and services provided?

Good practice includes:
- At minimum, for all rehabilitation services, including new and small organisations, to aim to conduct monitoring of the client population of a service, including information relevant to clinical practice, to service development and to human rights advocacy. This would mean that monitoring systems would yield information with three core uses:
  (a) To guide clinical/rehabilitation care plans and care;
  (b) To contribute to the planning and development of new and existing services; and (c) To contribute to human rights advocacy efforts.
- Organisations which have been established for some time and which have a range of services should aim to conduct additional types of regular monitoring. These organisations should conduct
  (a) as above, regular monitoring of the client population of a service, including information relevant to clinical practice, to service development and to human rights advocacy of service delivery; and
  (b) monitoring of service quality using audit projects focusing on specific aspects of service provision.

6.10 Monitoring focus

Having established which types of monitoring are necessary for the organisation, it is important to consider what the monitoring focus should be. Whilst the priorities for an organisation may be overall monitoring of client population, other priorities may dictate what the focus of monitoring should be. Monitoring focus may change depending on new funding, for example for particular new project-based services and donor requirements for accountability.

Key questions
- What components or aspects of services, or which services, should be monitored?
- What is a monitoring priority for the organisation, or for a particular service or project?
- How often should the focus for monitoring be reviewed by management
- Under what circumstances should a monitoring system be changed to accommodate new requests or newly-funded, time-limited project-based services?
- Who should decide what the monitoring focus should be? How?

Good practice includes:
- Establishing an organisational process for senior managers, practitioners and other staff to contribute to decision-making about which services, or standards are the priority for

monitoring
- Informing all staff of the priorities for monitoring, and changes to these, with explanations
- Periodically reviewing organisational priorities for monitoring

6.11 Questions for routine monitoring

Collecting information without a clear purpose and questions in mind often leads to many problems. Organisations can collect vast amount of information and details from clients but without knowing what to do with it, how to interrogate it to answer which questions.

The questions to be addressed may be from clinicians and other practitioners about their work, client needs, resources and strengths, or questions from team leaders about team practices, or the nature of referrals and client groups for example. Questions may be from donors, such as who are the perpetrators of torture, or questions from human rights advocacy officers and lawyers working with the organisation, such as what is the legal status of clients, how many have experienced certain forms of torture within a certain time period during a particular regime in any one country etc.

In some aspects, key questions pertaining to the client groups using rehabilitation services, their experiences of torture, their social, welfare, legal situation, their health needs etc. may remain stable over time. The questions organisations, and their donors, ask of rehabilitation service provision can change over time, with additional questions being posed which relate to current local contexts, or to developments in global events. For example, changes in national healthcare provision and national legislation may impact on the clients who come to rehabilitation services, or who may no longer come forward for services. Global crises, such as conflicts involving mass human rights violations, including torture, may provoke questions of how many clients from a particular country arrived and used services over a particular period, presenting with specific experiences of torture with reports of particular perpetrators. Some of these questions may be easily addressed from the information already collected. Some questions might not be addressed if the information required has not been collected in the first place.

A monitoring system which is fit for purpose is one which is clear about what information needs to be collected for what reasons, which questions and for whom.

Key questions:
- What do practitioners, managers, human rights advocacy officers and others need to know about rehabilitation service-use, about clients, about those who are not accepted as clients, about the quality of services provided?
- What information do donors and other stakeholders require?
- What specific questions need to be asked of the information collected in routine monitoring?
- What specific questions need to be asked for audit projects relating to monitoring service quality?

Good practice includes:
- Establishing a process which involves regular communication and joint effort within and across rehabilitation teams (e.g. for children, young people, adults); departments and functions (e.g. clinical, legal, fundraising, communications, management) in rehabilitation services to collectively identify and anticipate questions which need to be addressed.
- Collating a list of questions identified by the organisation, avoiding superfluous questions, duplication or overlap of questions, and clarifying exactly what information is required, for

whom and why

- Prioritising key questions so as to avoid a vast set of questions requiring vast data collection and numerous audit projects – which can block any monitoring process and demotivate staff and interfere with rehabilitation work with clients.
- Reviewing the list of questions periodically (e.g. annually) to update data collection and monitoring methods, and to anticipate what questions may be asked and which information may be needed in the near future
- Ensuring that all relevant staff and managers are engaged in this process of 'scanning the horizon', but also being clear on what are current practices and priorities for monitoring

6.12 Minimum data set

What is referred to here as routine monitoring (the regular, ongoing monitoring of services) requires agreement on a data set. A data set is information which it is necessary to routinely collect, record, analyse and report on. A data set should be the information necessary to address the questions posed by the organisation (see section 6.12) and information which is necessary to meet the goals of the organisation.

In the field of rehabilitation for torture survivors the requirement for data is complex and challenging for several reasons:

First, rehabilitation is a multidisciplinary activity (in that it involves many professionals offering interventions which are psychological, medical, physical, social, welfare, legal, educational etc.) and it requires professionals to work together, communicating across differing paradigms, professional trainings and professional terminology and concepts with different priorities for what information they need. Meeting each professional's/discipline's information needs in a routine monitoring system can yield vast, detailed and complex data which only they need and can use. For example, a physiotherapist or a psychiatrist may ask for specific information but not all other professionals providing rehabilitation will be competent in collecting or understanding the significance of that information, or need it themselves. In such situations, it is vital that information required by specific professions or teams be scrutinised to see whether it needs to be included in a routine monitoring system for all practitioners or in a sub-system for a particular profession or team.

Some of the information required for monitoring may be common to all professionals involved in providing rehabilitation. This 'core' information must be agreed between all professionals involved in rehabilitation service provision, and formulated in a language and form which all disciplines can understand and are qualified and competent to collect. An example of this may be the commonly used term "memory problems". The assessment of memory problems is a specialist skill requiring specific knowledge and training not common to all health professionals. Yet it is a commonly reported difficulty by torture survivors. A multidisciplinary service may decide that it is important information to collect routinely by all practitioners but it should be termed "memory difficulties" (as reported by the client), rather than "memory problems" or "cognitive/memory deficits" or "memory disorder" (which require assessment by those competent to make such clinical judgements).

Second, rehabilitation services can be provided as a "clinical" service or activity, focusing only on certain clinical interventions which exclude other interventions also recognised as components of rehabilitation for torture survivors (e.g. legal rehabilitation, social welfare support, educational and vocational guidance for social integration). Rehabilitation services are also often provided

within a human rights framework, where rehabilitation involves a range of interventions aimed at the individual and their family but also a range of prevention and human rights advocacy activities. The latter can give rise to another set of challenges in that the requirements for data collection have additional functions, seen as complementary and even central to rehabilitation. This is sometimes referred to as data collection for human rights purposes.

Clinicians may argue that information required for human rights purposes is irrelevant to clinical decision-making, care-planning and clinical rehabilitation. Deciding a data set for collecting routine information from clients then becomes an inter-disciplinary battleground. This can be further compounded if fundraising and communications professionals require other information routinely, to report to donors or for communication purposes, which clinicians do not prioritise or see as relevant to their own "clinical" work. Returning to the concept and standards of rehabilitation (clinical and legal understandings), and the organisation's service model and goals are then absolutely crucial to agreeing a minimum data set for information which is needed for the whole organisation, not just particular teams or professionals, to meet its service and organisational goals. This however does pose many challenges, not least in establishing robust information governance systems in the organisation which protect access to data. There is the need to ensure data integrity, particularly where information for the purpose of human rights monitoring would need to meet certain quality criteria, without which the quality of the data would not be assured, and therefore not be usable in human rights advocacy and prevention activities.

Third, rehabilitation does not involve one formula for all clients, which means that different information is required to monitor the common or unique features of particular rehabilitation approaches for particular clients. For example, some torture survivors may not feel comfortable to receive individual psychological therapy, though they may agree to attend an activity-based, support or therapy group with other torture survivors. Information may need to be routinely collected for all clients who attend group-based rehabilitation services; and for all those who attend individual rehabilitation services, but the information required may not be the same since the mode of interventions, type of service and goals of each service may differ. Agreeing minimum data set requires service providers to make decisions about what is routine, minimum information that everyone should collect for all clients and which specific, additional information should be collected routinely for particular services/interventions (e.g. groups, family services, vocational integration services)?

Fourth, many torture survivors are not able to provide all the information which a service may decide is crucial to them. This may be because torture survivors coming to services do not have access to that information (e.g. legal status, whereabouts of asylum seekers or of other family members); or they may not be able to recall important information (e.g. age, date of birth, medical conditions); or they may be frightened to disclose (e.g. nature of experiences of torture, knowledge of who the perpetrators were, ethnicity, sexuality, age – where age may be disputed in asylum claims). The safety of clients is also essential to address in data collection, as in some settings and countries, where the threat of further torture may be real for some clients, they may feel unable to share personal information for fear of what will happen to it, if states have access to it, how might it be used, by whom, for what purposes etc. The safety of staff working with torture survivors must also be of vital concern, since seeking specific information, such as on torture methods, and on documenting torture, for example, by the state, might create a risk of harm to themselves.

Organisations need to be extremely vigilant to these issues. Services might consider what is the minimum data which the organisation needs and which it will attempt to collect routinely, for all

clients. This may be in spite of knowing that practitioners may avoid collecting information which they sense the client is uncomfortable sharing or which clients themselves may decline to give.

Fifth, the organisation's needs for information can change over time, in response to changes in service provision, organisational goals, funding changes and other context changes. Hence, the minimum data set is not a static list of information, but one which needs to fit the changing priorities of the organisation and reflect the service model and goals. For instance, if an organisation is funded to respond rapidly to a regional humanitarian crisis, many decisions need to be made about which services are to be developed, using which model, which interventions and which information it is important to collect, for whom and for what purposes. Further, the services developed to meet such a humanitarian crisis may mean new types of services (e.g. community-based assessment, support and interventions within refugee camps or within the local community) not offered previously. An organisation will need to decide what additional, or different information is required, which was not necessary previously or routinely collected.

Key questions:
- Which particular information is necessary to meet the organisation's goals and the service goals?
- Who should be consulted to collect the range of information needed for routine monitoring?
- How will decisions be made about what is the minimum data set for all practitioners to collect routinely?
- How will decisions be made about what is additional, specialist minimal data required by certain practitioners or services?
- How regularly will the minimum data set be reviewed, how and by whom?

Good practice includes:
- Establishing a process which involves regular communication, consultation and joint effort within and across rehabilitation teams (e.g. for children, young people, adults); departments and functions (e.g. clinical, legal, fundraising, communications, management) in rehabilitation services, to collectively identify minimum information needed for monitoring in order to meet the organisation's goals and to reflect the service model.
- Consulting widely and senior practitioners and managers to identify information needs common to all practitioners, for routine monitoring; and specialist information required by specific professions or teams.
- Establishing a collaborative, mutually respectful and honest discussion between professionals to agree terminology for data collection which is meaningful to all, and within their competency to assess as part of routine monitoring.
- Ensuring that the minimum data set agreed can fulfil differing functions within the organisation (e.g. clinical care-planning and monitoring, human rights monitoring, reporting to donors, strategic planning and service development) and that the data set reflects the concept and standards of rehabilitation, and the organisation's service model and goals.
- Ensuring sensitivity to difficulties clients may have in providing information considered as crucial to the organisation, and anticipating implications for data collection and analysis (see 6.15 and 6.20).
- Reviewing at specified intervals, and wherever required, changes in the organisation's needs for information needed for routine monitoring.
- Sharing the minimal data set agreed to all staff and across all levels of the organisation, so that information is understood and valued as 'organisational information' necessary for the whole organisation to meet its goals. (For a sample of a minimum data set, see Appendix 1)

6.13 Designing: routine monitoring or audit projects?

Designing a monitoring approach is a two-fold task. Organisations will need to decide

(a) what can be routinely collected, for example, general information for every client, and specific information for clients using particular services; and

(b) what specific information may be needed to audit particular aspects of services.

Routine information monitoring requires a design which allows for the collection of data routinely, with every client, and which can be analysed at specified intervals (e.g. every 6 months, annually).

Audit projects require a design which fits the specific audit question which may be for one particular activity (e.g. auditing how well risk is assessed and documented by clinicians) across the organisation, or a questions which focuses on one particular service, or project (e.g. auditing how well the protocol for working with external agencies, such as state medical services, or another NGO, providing care to clients 'shared' by those services is adhered to). Audit projects can be small-scale or large-scale, and initiated at any time or alongside and in addition to routine monitoring. Conducting audit projects to improve the overall quality of services is addressed in section 6.28.

Key questions:

- What is the organisational priority and capability currently: to conduct routine monitoring alone; or to conduct routine monitoring as well as specific audit projects?
- What do we need to know about our services and clients' and more specifically 'what should we look at closely, how and with whom, in which area of the service?'

Good practice includes:

- Establishing a process which involves consultation and joint effort within and across rehabilitation service teams (e.g. for children, young people, adults), departments and functions (e.g. clinical, legal, fundraising, communications, management) to collectively prioritise monitoring for routine monitoring and/or audit projects.
- Ensuring that an organisational culture is fostered – a culture of reflection, interest in the quality of services, commitment to improving services and recognition that conducting routine monitoring and audit are ultimately a matter of ethical and professional practice in the interest of torture survivors and their families.

6.14 Designing data collection methods

Data collection methods will depend on many factors, such as who will be required to collect data and whether they have an appropriate level of knowledge and skills to collect such data. For routine monitoring, there is usually an expectation that all clinicians involved in client care share basic knowledge and skills necessary to collect routine information. However, what is considered routine information may be subject to inconsistencies, depending on the clinician's professional training and qualification, their skills and knowledge. Examples include: who can assess and document whether a client has "memory problems" (see earlier section 6.13), or whether a client is at risk of suicide or harm to others, or is suffering from the effects of brain injury as a result of torture. Careful decisions need to be made about how best to collect information, and whether further training is required for some or all staff on particular areas to improve the quality of care and of data collection

Data collection involving personal information obtained from clients, including health-related information, is a process which is bound by strict ethical, professional and legal codes (as

relevant in the national context). It is important that unrealistic expectations are not placed on staff to collect information which they are not competent to collect. One example is where legal practitioners, or a legal advisor, may conduct their own assessment with a client but be required by the organisation to document any concerns about the person's psychological or medical health. Here, it would be unethical to expect the legal advisor to use the same data collection method as a clinician collecting the same information. Data collection systems may then have to be differentiated to not breach ethical, professional and legal codes.

Data collection methods also have to be realistic, efficient and non-intrusive as possible for the client in the provision of rehabilitation and client care. Expecting staff to complete a battery of extensive tests, tools, questionnaires and forms may serve the organisation's priorities but be experienced differently by clients, and seen as "asking what you need to know for you, not what I want to tell you". Clients can also be overwhelmed and feel bombarded by the volume and detail of information asked or required of them, and good clinical practice in assessment and in interventions must be considered to always ensure the client's best interests.

Data collection which involves free text based on interviews with clients can be very useful to aid communication and relationship-building with clients since it does not require practitioners to be driven by extensive forms, tests, questionnaires etc. However, free text is very difficult to use meaningfully for routine monitoring purposes, as it requires considerable time and specialist knowledge and skill in qualitative information analysis.

Any routine monitoring usually requires more resources than are easily available, particularly since routine monitoring involves collecting information with every client. An elaborate system without adequate resources is likely to risk wasting effort. There are various ways to address this challenge. One may be to limit data collection to a staff group with appropriate skills and knowledge to collect information, rather than expecting all practitioners to collect the same information for every client. Another may be to collect data from all clients at specified and, if possible, multiple time points. This could be, at minimum, at the beginning and at the end of all rehabilitation, with all clients. Where resources and skills are available, additional time points may be useful to collect data, such as every three or every six months. Rarely services may decide to collect information for each client after each session, which for many may be weekly.

The process of collecting data is extremely important. Clients' views should be respected, and the impact of data collection on them should be a central consideration to all data collection activities. Clients also need to feel that their views are respected, that their responses are valued, and that practitioners see them and treat them as human beings, not as objects from which to extract information required by the organisation. They must also feel they can be honest and provide feedback on their experiences of the service and of the process of completing questionnaires, being asked for information etc., without fear of negative outcomes for them for the care they receive, or the fear that services will be withdrawn or denied to them.

It is important to recognise that the points at which data are collected generate their own pressures: at the start, a client may feel that s/he needs to emphasise need, or may fear stigma, judgment and shame in the presence of strangers (e.g. by the clinician and/or interpreter) by minimising it. Similarly diverse pressures operate at assessments, at routine intervals during the therapeutic process and particularly at discharge or the end of service provision. Engagement, explanation, and clear information about what the data is for, who sees the data and how they are kept are particularly important for torture survivors who may have had clinical records previously

traduced for the purposes of planning or intensifying torture methods.

The issue of confidentiality is relevant to data collection. Whilst routine monitoring can require considerable personal and very sensitive information, it should ensure anonymity in analysis, reporting and respect confidentiality at all stages of the monitoring process. It is an ethical obligation to provide adequate information to clients regarding routine monitoring so that they can be assured that their personal information is used only for clinical purposes by those involved in their care, unless informed consent for any other use is provided by the client.

Clients should be informed that personally identifiable information will not be used in any routine monitoring conducted by the organisation, and that all such information will be anonymised. This may involve developing a robust system of anonymisation of client information throughout the routine monitoring process, from data collection to reporting, for example by providing a unique, protected, identity number for each client, which cannot be directly linked with any personally identifiable information. However, even anonymised data could enable identification of individuals, for example where they are from minority groups, or one of few people with particular experiences of torture etc. Wherever possible, all measures should be taken, including the use of 'meta-data' which does not compromise confidentiality and the safety of any client or their family.

Key questions
- How should data be collected, by whom, when, how often?
- What skills are needed to collect the relevant data?
- Who has the relevant skills to collect data from clients?
- What form of data collection will be least time-consuming and most effective in obtaining the relevant information?
- In what format should information be collected (free text, numerical values, tick boxes, yes/no, scales etc. to ensure consistency, efficiency, integrity of data and interpretability?
- How can routine monitoring protect the interests of clients and the impact on them?
- How can clients be informed of what routine monitoring is and implications for them?
- How can client information be protected and confidentiality assured in routine monitoring?

Good practice includes:
- Ensuring that those who are required to collect client data for routine monitoring are competent to do so.
- Ensure that data collection methods are respectful to clients, non-intrusive, non-burdensome, efficient, acknowledge the impact on clients and do not detract from or hinder therapeutic contact with clients.
- Ensure that organisational policies, procedures and clear protocols are established to ensure the confidentiality of client information, and processes of anonymisation for routine monitoring.
- Ensuring that data collection methods minimise the burden on clients (e.g. with a battery of tests and questionnaires), minimise wide variation in quantity and quality of data collected, and minimise inconsistencies in data collection which make subsequent analysis and interpretation difficult and unreliable.

6.15 Monitoring tools
Developing tools for routine monitoring is a process which requires the establishment of tools which collect the minimum data agreed by the organisation, and a process to update such tools, as required.

Rehabilitation centres may develop their own routine monitoring tools to meet their own needs, or use them in combination with other tools, which may include specific standardised measures, for example for assessing trauma or depression symptoms. There are benefits and disadvantages to both approaches. For example, routine monitoring tools specific to one organisation may reflect very well the services provided, the organisation's specific remit and goals, but it may also mean that some specific information is collected, which other organisations do not collect, or that it is collected in a different way, using different criteria and questions. If such information would be crucial to human rights monitoring, across rehabilitation centres in a region, for example, different data collection methods across centres would hamper, if not preclude any meaningful collation, analysis or interpretation of the data. Similarly, using standardised tools might provide an opportunity for some comparison across centres, or some pooling of data for research or other purposes, but typically these tools lack cross-cultural validity, limiting any meaningful interpretations, and they tend to focus only on particular symptoms or difficulties experienced by torture survivors, and are then partial (for further discussion see Section 8).

The number, format, length and time taken to administer routine monitoring tools is also need careful scrutiny. Data collection can be seen by practitioners, and experienced by clients, as a tool primarily for the organisation, but one which creates strain on practitioners or those collecting data, and on clients. This may mean that data collection is carried out and treated as a routine chore unconnected to client care, at the expense of clients and their experience of the services they receive.

The decisions made about data collection methods will influence which and how many monitoring tools are used by an organisation. If it is decided that routine monitoring is to be collected only at assessment, at the beginning, and at the end at the time of planned or unplanned ending of rehabilitation, then the monitoring tools will be developed to reflect those decisions. If it is decided that a collection of tests will be used for all clients every month, or less frequently, then monitoring tools may be designed to reflect such a decision, and will be influenced by how those tools are to be used (manually, computerised etc.).

Monitoring tools may take many forms: questionnaire, self-completed form, or forms to be administered by a practitioner, or administrator or other staff member, forms which are semi-structured, with some sections as questionnaires, other sections left for open-ended text, forms with specific questions and scales. A questionnaire format allows data to be collected more consistently across professionals and facilitates data entry into a database. A semi-structured, part open-ended format may be useful where the narrative of a person's experiences of detention, or their family relationships, for example, are explored. However, free text, with its wide variation reflecting the professional style and working methods of each practitioner, can make the information difficult to analyse and interpret for routine monitoring purposes, though facilitating therapeutic rapport and decision-making about each individual or family's care plan. A balance has to be struck between what is absolutely necessary from the perspective of therapeutic process and rapport-building and what can be routinely measured for monitoring.

Monitoring tools may need to be completed by practitioners and some tools may be completed by other staff, depending on the knowledge and competencies required to use such tools.

Monitoring tools may also need to be developed to reflect the different services and their focus and priorities, which may not be relevant across the whole organisation or across all services

provided. For example, clients offered group therapy or family therapy, or social welfare guidance may require particular information not required or assessed by others. Even within a service, for example, clients provided groups as a form of interventions, there can be differences in that they may be seen by professionals with differing training, skills and priorities about what needs to be routinely monitored and how. Intra-service differences (due to a range of professionals from different disciplines and trainings) may exist in methods of data collection, even if the same monitoring tool is used. All these variations may result in data collection which is less and less amenable to meaningful analysis and interpretation, and which leads to demands for more and more 'separate' monitoring tools for each service, each profession etc. This can lead to fragmentation in the approach to routine monitoring, and numerous, weighty monitoring tools which demotivate staff and clients. Again, a balance has to be struck between what is necessary to facilitate therapeutic rapport and what is crucial for routine monitoring to ensure quality service provision.

Examples of monitoring tools using a minimum data set can be found in appendix 2.

Key questions
- What is the best way to obtain the information needed?
- Which type of tool will facilitate routine data collection and meet organisational aims?
- What is the best format of routine monitoring tools: paper, computerised (self-completed or practitioner-led)?
- How many tools are needed and when should each be used?

Good practice includes:
- Developing monitoring tools which are user-friendly, designed to collect information efficiently and as unambiguously as possible, and in a way that is amenable to analysis.
- Developing monitoring tools which can capture the minimum data needed to (a) support and facilitate the planning of care and subsequent rehabilitation for clients (focusing on needs, strengths, resources and circumstances of clients); (b) to meet the requirements of the organisation to ensure quality services; and ideally (c) to support human rights monitoring and prevention activities.
- Developing tools which take into consideration the need for interpreters throughout any information gathering, which is time and human resource-consuming
- Developing tools which strike a balance between what is needed by the organisation itself, and what is needed for pooling data or comparison with other similar organisations or services (e.g. in the region, globally), whilst ensuring that clients' best interests remain central to all decision-making.
- Consulting staff and all relevant professional groups, on the nature, format, quality, user-friendliness and number of monitoring tools, and their format (paper, computerised etc.), ensuring regular opportunities to review and revise monitoring tools as appropriate.
- Pilot all monitoring tools and their application (paper form, manual, computerised etc.) and revise as necessary, taking into account their user-friendliness, efficiency, meaningfulness to practitioners and to clients, amenability to data entry, analysis and interpretation.

6.16 Data recording
Data recording refers to where the data is actually recorded when it is collected.

Data recording is a critical point in any routine monitoring system, and the usefulness of subsequent analysis and interpretation depends on what information is recorded and how. Data

recording is subject to human error, and can be influenced by time and clinical pressures faced by clinicians, work load, and fatigue, as well as ambivalence about or resistance to recording data and to any form of monitoring or evaluation.

Data recording can take many forms and may depend on resource availability, staff preference and what is feasible and most efficient and least prone to inaccuracies and missing data. Commonest forms of data recording are using paper, or using electronic methods.

Practitioners may be asked to complete paper copy versions of monitoring tools which may then be stored in client files, as well as entered in databases. Practitioners may also be asked to use computerised systems to enter data directly on a computer screen themselves, or for an administrator to complete part of the monitoring tool, leaving other parts to be completed by the practitioner. Computer systems can also be designed to minimise the repeated collection of the same information in different monitoring tools, or where monitoring tools are used repeatedly at different intervals – for example by populating certain information fields from earlier records, allowing options to update where necessary.

Manual, 'paper and pen' methods of data collection pose various challenges but can be the most practical. Monitoring tools, including standardised measures and questionnaires need to be accurately copied so that items are exactly represented, and so that there are no missing pages. They also need to be checked after completion.

Where monitoring tools need to be completed by clients, it is essential that these be professionally translated. Where standardised measures are used, validated translations must be used and, where these are not available, they must be translated according to established standards, whilst recognising ethical implications and shortcomings of using non-validated translated measures (for further discussion on translation and validity see Section 8).

Where clients have completed some or all of the monitoring tools, it is essential to check (with the help of an interpreter wherever necessary) after completion as it is easy for clients to miss questions or even whole pages, though this might make the incomplete instrument unusable. It is also helpful for practitioners, appropriately trained, to be available to clarify meanings for the client who finds questions puzzling, without suggesting answers. This is all time-consuming and sometimes onerous for clients. Data recording should not be a burden on clients and sensitivity to the impact of such obligations on clients, and clients' experiences of monitoring tools, is essential to feed back when refining monitoring tools. As with all aspects of routine monitoring, clients' best interests should be kept in the forefront and their well-being not compromised for the sake of collecting information.

Electronic methods for data recording may be used instead of paper methods, where appropriate. For instance, routine monitoring tools can be available for each practitioner on a computer, and data entered directly either during the session for some types of monitoring or after a session, where supporting notes may be used. Generally, staff entering data onto computerised monitoring tools during a clinical session or consultation is inadvisable, since it can interfere with rapport-building and the therapeutic process, hindering rehabilitation efforts.

Some monitoring tools, such as standardised measures or structured questionnaires may be used electronically, though this requires considerable thought and planning to ensure that any data collection and recording methods do not counteract the rehabilitation process. Computerised

questionnaires, on a screen of a fixed computer or on a tablet, can be useful in some settings. They can also be useful when designed to give verbal requests, in the language of the client, and when they prompt clients if they miss items, though this can be experienced as punitive and anxiety-provoking (fear of getting an answer 'wrong' or being forced to respond on an item or question they would rather not respond to). If such methods were used, it would be possible for questionnaires to be summarised and where necessary (e.g. where standardised measures are used) for scores to be calculated automatically and sent to an anonymised file. However, in some settings, these methods may be inappropriate and impractical. Further, such methods can be experienced as impersonal, frustrating and anxiety-provoking and it may be useful to have someone available to answer clients' questions, to support them and to explore their anxieties and fears as appropriate. So far, most comparisons of pen-and-paper with electronic methods of completing questionnaires show no significant differences, but these studies have largely sampled western populations which are conversant with both media.

Personnel considerations are important. It is common for neither clinical nor administrative staff to feel that it is their job to administer, collect, and process monitoring and evaluation instruments, and this can hinder monitoring which relies on routine data collection and recording. In the case of routine outcome monitoring, ideally data collection and recording should be conducted by someone not involved in treatment as this may otherwise be experienced as coercive by clients. They may feel unable to report lack of change in their symptoms, for example, or feel that they may offend or anger the clinician if their lack of progress is seen as a reflection of the competency of the therapist. Alternatively, they may feel that they want to please their therapist and tend towards exaggerating progress. For clinicians, too, having to administer routine monitoring tools and recording responses from clients can feel like an onerous task and one which detracts from the therapeutic process. There are no easy solutions to this and often pragmatism and resource availability may dictate what methods are used.

Assistants or interns, often graduates gaining relevant experience before further professional training in social work, psychology, medicine or similar, can be competent to do this work, can be trained and supervised to collect and record client data, and should have the necessary interpersonal skills to relate to clients. Asking clients to take the relevant questionnaires/routine outcome monitoring tools with them, to complete on their own, and to return them at their next visit/ session or by post, is not advisable. It is a method which places considerable responsibility, and added strain, on torture survivors who may already be struggling with many daily life and health concerns. Generally, this method also results in large scale loss of data by non-return, partial return, or return too late to identify and obtain missing information. Obtaining responses from clients by mail (or by phone, with the help of interpreters where necessary) is another method available but this requires access to phones. It also requires regular prompting and constant updating of received and outstanding responses which is very time-consuming and rarely comes close to the response rates obtained from routine monitoring during or after sessions.

As with all aspects of the routine monitoring process, it is important to pilot data recording, to check how data is being recorded and if it is being recorded according to agreed protocols established by the organisation. Waiting annually to check data collection and recording practices can result in missing data and problems which cannot be easily, if at all, rectified. Data which is incomplete or recorded incorrectly is unusable.

Various methods can be used to check the way in which data is being recording. Those responsible for data analysis could sample periodically to identify missing information, inaccuracies and other

errors in recording, and provide feedback to the relevant managers about the key issues, so that they may be corrected and practices improved. Where data is entered by a designated person, they may systematically note common errors, missing data etc. and return paper records to the responsible clinician to correct, before data is entered in a database. A more rigorous method would entail a process of double data entry where 10% of data already entered is selected at random and entered independently by another person. Results should then be compared and if the error level at original data entry is over 2% all data should be re-entered.

Key questions
- How will data be recorded, where?
- Who will record which data where?
- How will data recording be monitored, by whom?

Good practice includes:
- Agreeing an organisational process with practitioners, administrators, data entry staff and others on how data will be recorded, who will be responsible for recording data, and where (client files/computerised system).
- Piloting data entry procedures and refining the system based on the outcome
- Ensuring there are mechanisms for monitoring the quality of data recording, to ensure accurate, and meaningful data entry which minimises missing data

6.17 Data collation

Data collation is the process of gathering and organising all data recorded, in whatever format. It is the necessary stage before preparation for data analysis, since data which is not appropriately organised cannot be systematically analysed.

The methods for data collection and recording may dictate how data is collated, to minimise further work in sorting and organising data. There needs to be a system to enable data to be used for all the desired functions it was designed to fulfil (e.g. clinical care planning, human rights monitoring, rehabilitation service planning) in a timely fashion. For example, data collection which involves the gathering and recording of a wide range of clinical information may need to be immediately accessible to inform clinical decision-making. Hence, where paper records of client data are used, they need to be accessible readily within client files and cannot wait for a process of data entry in a centralised database before being returned to client files. Entry into a database would be necessary for data collation and analysis, for example, to establish for aggregated data to monitor human rights violations from a particular country.

If paper-based records of client information are used, then the same records or duplicates would need to be sent and returned promptly to the person or team responsible for data entry. Alternatively, those responsible for data analysis may be required to manually sort paper records and data, anonymising them prior to any analysis.

Another possibility is to have practitioners enter data themselves, directly onto a computerised system, which means that the data is accessible promptly to all those who need it and who have authorised access and that the data can be organised according to defined protocols at the point of recording. This minimises manual data collation, but places a further burden on practitioners to gather and record client information promptly and accurately, and as noted earlier, can interfere with the therapeutic process if carried out during sessions. Also, computerised systems need to be robust, comprehensive and designed to minimise errors and missing data.

The timing of data collation is an important consideration. Ideally, as noted before, direct data entry and collation at the point of entry minimises delays and allows data to be readily available for analysis at any time. This may not be practical and an alternative is to develop a method which can allow periodic data collation at, say, every 3 months.

Where monitoring tools have been completed in paper records, it may be useful to create a system where the measures are scored, any added comments or messages noted, and the scores entered on an anonymised spreadsheet which uses only a client number to which the key is kept separately. This process of collation, including the checking for the appropriate completion of information on client-data forms or monitoring tools, scoring, and entering the scores, takes considerable time. Yet collecting often incomplete monitoring tools, then leaving them unscored in clinical files, will mean that the data is most unlikely ever to be collated and used, which not only compromises organisational goals but raises ethical questions. It is unethical to seek and obtain information from clients which is then not used at all or not used for their benefit and for the benefit of the organisation providing their rehabilitation services.

Key questions
- How should all the data collected be gathered and collated
- Who should collate data, when, how often?
- Should outcome-related data be scored at data collation point, and by whom?

Good practice includes:
- Establish a system for data collation which allows client data to be accessed and used for all agreed organisational functions and goals (e.g. clinical care, organisational development, human rights monitoring).
- Ensure data is collated promptly and regularly
- Ensure data collation is seen as an essential step in routine monitoring, and that the collection, without facilitating access to and appropriate use of client information, is understood by all staff as an ethical breach.

6.18 Data storage and retrieval
Building a database where data can be entered and stored systematically will facilitate the process of data checking and analysis and highlight any emerging problems with data collection. It will allow efficient use of client-related information by the organisation. Database requirements for an organisation may be diverse and substantial since client-information collected can have many functions and be used by clinicians, managers, legal advocacy and research staff, fundraising staff etc. Decisions need to be made about how many and what type of databases should be developed for which function.

Database development has resource implications – establishing a database requires considerable time for consulting all relevant parties, for the designers to be fully aware of all the requirements of the organisation, for the design, piloting, refinement and full implementation of the database. Databases may also need to accommodate some changes and have some flexibility, which also requires resources for periodic updating, though anticipating all requirements can minimise costly changes, or worse, the need for another database, later. Identifying commercially available databases may be one option, though they may be costly, and not fulfil all the specific requirements of the organisation in question. Developing a database from scratch is another option but, again, this can be a costly exercise requiring extensive consultation, which may in the end be a question

of 're-inventing the wheel', resulting in a database not that different to pre-existing databases.

Ideally, whatever the database, it should be possible to collect and store data in programs which allow statistical analysis (e.g. SPSS, R, STATA etc.), or in programs that allow the data to be extrapolated and transferred to programs which would then allow statistical analysis (e.g. Excel, Access etc.). For most purposes, Excel spreadsheets or equivalent are a manageable way to record data, since text as well as numbers can be entered. They may not, however, fulfil all the functions required by the organisation. Nevertheless, Excel spreadsheets can be easy to manipulate to extract data, with experience in data handling which is considered essential. Unfortunately, it is all too common for charts and graphs to be generated from data by staff who do not have adequate understanding of the content or of the apparent implications, for instance, of the quality of data, or of missing data. The retrieval of data for analysis therefore needs to be carried out by those with appropriate knowledge, skills and experience.

Access to data and the retrieval of data stored raise many crucial ethical considerations. The safety of clients and the privacy of information relating to them must be a paramount concern at all times.

Client-information is subject to ethical obligations, including confidentiality. Data storage which is used for clinical care and other related functions, which cannot rely on anonymised data, must be strictly protected in keeping with professional and national legal standards (the latter may vary in different countries). Access to such data storage must be equally guarded and restricted only to personnel who have authority to access specified data. Rarely can any person have authority to access all clinical data for all clients. Clinical data, for example, cannot be accessed by clinical or human rights researchers, or by fundraisers, in unanonymised forms, even if data access is a core component of their work. Client consent for access for each clinical record would be normally required according to professional and most legal codes.

Data in anonymised forms can be accessible, for example for routine monitoring, if clients are fully informed at the outset that this is what the organisation will do with it. Confidentiality is a very serious issue and data which need to be analysed for routine monitoring purposes still have to be first transferred into an anonymised form before any analysis can take place. For routine monitoring which involves access to data for analysis and summary, there is no need for names, nor for identifiers such as address, date of birth, next of kin, and other administrative details, to be attached. Therefore, any file linking these details to the individual identification number for data used in the analysis should be passworded or encrypted and kept separately and securely from client records.

Key questions
- How should data be stored?
- What are the requirements for a database?
- Who should have access to which part of the database?
- What systems will be established to ensure ethical practice with regards to data storage and access?

Good practice includes:
- Consulting widely in developing databases to ensure that data storage systems meet the requirements of the organisation.
- Identifying resources available to establish, and to subsequently develop and maintain data

storage systems.

- Conducting a pilot of the database, and for the purpose of routine monitoring, to refine the database and related systems and practices, before full implementation and 'going live'.
- Establishing an organisational policy and procedures to specify who has access to which aspect of the database, for which purpose.
- Ensuring all aspects of data storage, access and retrieval are subject to strict control and adhere to professional ethical codes, and to national legislation regarding data protection and access to health-related, and human rights-related information.

6.19 Data analysis

Data analysis requires a postgraduate level of research skills (for instance, an MSc). Where those skills and knowledge are not available within an organisation, partnership with a local university department could be a route to enabling data analysis, since analysing and reporting data can be part of a postgraduate research-based degree, and can be supervised by an experienced academic. This means that there are highly likely to be ethical, data protection, and other concerns that need to be carefully considered, agreed and monitored.

Preparing a data management and analysis plan at the outset is a good time to consult those who need to use the data collected, to be clear what is being asked of the data. Deciding which methods are needed for data analysis will depend on the questions originally agreed for routine monitoring, as well as questions identified and prioritised by the organisation (see section 6.12). The application of methods of analysis and the interpretation of results, requires competency in statistical analysis, an understanding of what the results mean, what they do not mean, and of the limitations of the analysis.

There are various stages to data analysis, whatever the method, which are important to understand. Throughout the process of data analysis, it is vital to document all stages and, where appropriate, to include them in reporting, depending on the audience and the level of detail required. In any case, justifications for data analytic methods need to be accessible by others to establish the reliability of the findings and possible interpretations. The documentation of data analytic processes can also help make transparent and justify choices made in the analysis, (including which data were excluded and why) and help staff and managers understand the process.

The first stage of analysis is data 'cleaning' and checking for errors (e.g. checking for duplicates, inclusion or exclusion criteria, outliers etc.) and distinguishing missing values from data where the true value is zero. Unlikely values (such as age over a particular value, such as 80) can be checked and corrected where they have been mistyped. As far as possible, missing values should be pursued, and often it is helpful to distinguish between those missing because the questions were not asked of clients and those missing because clients did not respond.

The second stage of analysis requires further attention to missing data to establish what proportion of data is missing, for which fields (e.g. gender, experience of torture, family details, legal status of family members, health outcomes) and explanations (e.g. the questions are too intrusive, worded insensitively, clients do not have access to information asked etc.). Missing data are common but, given that any response rate will inevitably be less than 100%, the question arises of what rate is good enough, and how complete does the data have to be for meaningful analysis and interpretation.

In the use of routine monitoring tools (such as clinical outcome monitoring tools) there are two

related issues with regard to missing data: the likely range of responses among those which are missing, and the reason they are missing. If missing clients was a truly random process, then the missing values could be assumed to be similar to those that were collected, and therefore results from those collected could be generalised to the entire population. But it is extremely rare for data to be missed at random: it is much commoner that certain clients (the most dissatisfied with services, perhaps) avoid supplying them; that certain clinicians discourage their clients from completing them; or that other biases apply, such as clients arriving to the service outside normal working hours or late for appointments; or those who are most distressed or difficult to approach. It is very common to find it difficult or impossible to collect data from clients who are relocated or dispersed, who are detained, who have no fixed address or are homeless, or who for some other reason are mobile. If such clients are missed, they may constitute a sub-sample whose scores are not represented by group averages of those who have completed them, but who may be more distressed than other clients, or dissatisfied, or have greatest needs or difficulties, or who may be making the slowest progress. This means that their unknown scores cannot be represented by those that were collected. Had they been collected, they might have significantly altered the overall mean scores and the impression they give.

In some situations, missing data can be identified early, at the point of data collection or data entry, and practitioners can be asked to prompt clients again to establish what information is missing. Other options include ensuring there are clinical assistants or interns who can be appropriately trained, supervised and authorised to seek key missing data (e.g. gender, country background) from client records, where the information is recorded in client notes, but not using the agreed monitoring tools. Both options are highly time-consuming and hence inefficient and costly but they may be last resorts if the data available are compromised by the missing data on key fields such as gender, for example.

Once the data set is as complete and correct as far as that is possible to ascertain, the third stage in data analysis involves deciding which data can be subjected to what type of analysis, for what purposes: summary descriptive analysis, or more advanced analysis establishing patterns, differences and relationships between variables (or data fields e.g. gender, country background and type of torture).

When summarising data descriptively, where values are not represented as dichotomous (such as gender), they may be categorical (such as civil and asylum status), or they may represent a scale (see above) of difference in some continuous quality or property, such as age, number of children, or score on a questionnaire. Categories, whether two or more, are usually described using the actual number and/or the percentage.

Scales are often best summarised rather than represented as categories. One of the commonest summaries is the mean (or average), which is the total divided by the number of values contributing to the total. Thus, if there are 10 clients, two with 1 child, two with 2 children, 2 with 3 children, 2 with 4 children, and 2 with five children, then the mean number of children is 30/10 = 3. However, 3 would also be the mean for another 10 clients, of whom 7 had 1 child, one had 5, and two had 9 each. In that case, it might be better to describe the clients in the categories of having one child, and having more than one child. Because the arithmetic mean does not differentiate between these two different groups of 10 clients, it is common to add a measure of spread, or variance. This can just be maximum and minimum: so for these two examples it would be for the first 10 clients a mean of 3, minimum of 1 and maximum of 5; for the second 10 clients a mean of 3, minimum of 1 and maximum of 9. This may be enough to provide a general impression of the extent of spread of

the data. A further way of representing the variance in data is by the standard deviation, which is the square root of the variance and for the two examples above would be 1.5 and 3.4 respectively. All these descriptors can be generated within Excel and similar software.

Using these simple characteristics, it is useful to ask further questions of the data, such as whether clients differ in the services offered or taken up; are there changes in service delivery year by year, such as in the mean number of sessions per client; are there changes in the client population over time, are there patterns in methods of torture used and reported by clients from one country over a specified time period, is there a relationship between gender and methods of torture used, and is there a change in practices of torture in one country within a specified time period (where data can be compared across years, for instance)? These questions can lead to identifying changes in client group, their experiences, needs etc., and in practice, which might not have been evident otherwise. This can lead to review of whether action is needed in relation to these changes. Such questions can also fulfil the differing functions required of routine monitoring, for use by rehabilitation service managers, clinicians, human rights advocacy and planning of prevention activities etc.

The timing and frequency of data analysis is important to decide. Organisations may choose to conduct annual data cleaning, checking and analysis for reporting purposes, or where possible, to conduct quarterly or 6-monthly analyses. Analysis can also be conducted at any time of the year, to respond to emerging questions, for example, in response to a crisis or human rights advocacy potential. However, the latter relies on existing data to have been cleaned and checked for missing data prior to any analysis – a process which requires appropriate skills and time to respond. The timing and frequency of data analysis is usually a decision shaped by resource availability and organisational priorities for data reports for different purposes.

As with all stages in routine monitoring, ethical issues are vital to consider. Data description needs to be constructed with regard to confidentiality, so that, for example, if a service has a relatively small number of clients, describing them by age or country of origin could identify those who are outliers or the only client from that country. Where clients from a particular ethnic background or country are in the minority, again, data description could make them easily identifiable and breach confidentiality, and also risk their safety in some contexts. If such information has to be summarised and reported, for instance, country of origin, then other data should not be described or tabulated with reference to this. Additionally, in examples of casework described to convey complexity, unique combinations of factors too closely specified could identify the individual involved.

Key questions
- Who can analyse data?
- How should data be prepared before analysis commences?
- How should data be analysed?
- When or how frequently should data be analysed and summarised?
- What ethical considerations are relevant?

Good practice includes:
- Establish before any data analysis is conducted the level of skill and resources necessary, and identify relevant personnel.
- Ensure data is cleaned and checked, the proportion of missing values and possible reasons established before analysis.

- Establish a data analysis plan, identifying which methods are to be used to address the needs and questions posed by the organisation in relation to the data.
- Ensure the frequency and timing of data analysis meets organisational requirements, but which is realistic in terms of time, resources and the availability of necessary competencies.
- Ensure that ethical considerations are given full attention and measures taken to ensure the safety and well-being of clients.

6.20 Interpretation of the data analysis

Interpretation of data essentially is a reflective process which asks the questions 'What do the data mean? What do analyses tell us?'

Interpreting data requires appropriate knowledge and skills in research methods and adequate understanding of rehabilitation practices and service provision. Data interpretation cannot be left to individuals to do themselves and there is an obligation to ensure that findings from data analysis, including basic summary, descriptive analysis involving percentages, are supported by accompanying interpretations by those competent to understand what the data could or could not mean, and to ensure that there are no spurious extrapolations and interpretations made where the findings are distorted, or misunderstood.

Following interpretations of data analysis, a range of staff, such as senior clinicians, or managers, or administrative staff responsible for data entry, or for managing client referrals, may need to be consulted to identify other interpretations of the findings, or to rule out explanations. Such a process may also clarify any additional questions which need to be asked of the data, to better understand what the data mean, and whether, for example, the organisational goals, or remit, are being met.

Ethical considerations apply to data interpretation and there is an ethical obligation for interpretations to not only be undertaken by those qualified and competent to do so but for them not to be distorted, manipulated or misrepresented for any reason.

Key questions
- What skills are required for interpretation of data analysis?
- How should findings from data analysis be interpreted? What do the data mean?
- Who should be consulted to consider various interpretations?
- Are all questions agreed for routine monitoring addressed by the interpretation of the data analysis?

Good practice
- Ensure data interpretation is carried out by those with the appropriate skills and knowledge, and identify relevant personnel.
- Explore alternative interpretations of the data and consult widely to better understand the findings from data analysis.
- Ensure that all questions agreed for routine monitoring are addressed by the interpretation, where possible, and explanations for why data cannot be interpreted reliably provided where questions cannot be answered.
- Ensure ethical practice in all interpretation of data, to avoid distortions or misrepresentations of findings.

6.21 Reporting

Reporting refers to the presentation of findings. Reporting on findings depends on who needs to see them. The same findings can be presented in different formats, and detail, depending on the intended audience. For example, service managers seeking to understand provision and where practices need to be improved (e.g. on minimising missing data) may need detailed reports which provide full explanation of what are the difficulties and possible explanations for missing or incorrect data. Donors may need responses to some questions and other findings may not be relevant or required. Reporting findings appropriate to the audience therefore requires understanding of different needs.

Reporting on findings also necessitates relevant knowledge and skills, especially in research methods and in understanding data analysis and interpretations. Reports may be prepared by a number of people with skills in research methods, including those with understanding and skills in quality monitoring and enhancement, so that reports can clearly articulate the implications of the findings for different audiences.

Summaries of data and findings in reports need to be as complete as possible, but well organised in order to give an overall context for the detail of the findings. Reports may vary for each audience but should provide both quantitative summaries and narrative explanations and discussions of the findings.

The timing of reports can pose a challenge where different audiences and stakeholders have different time-scales. Ideally, data preparation, analysis and interpretation can be done periodically (e.g. every 3-4 months) or, at maximum, annually to ensure reports are available regularly. However, this process is time- and labour-consuming and, if at all possible, comprehensive data analysis for all client-related data across the organisation should be conducted at intervals which are realistic for the organisation but do not compromise the integrity of the process and quality of reporting.

Reports are an important communication tool for highlighting the key implications of the findings, trends, gaps, difficulties, good practice and areas for improvement or further investigation.

Key questions
- Who needs to see the findings?
- How should findings be presented, in what format and detail for which audiences?
- Who can prepare reports on the findings?
- When should reports on findings be prepared?
- What should reports contain?

Good practice
- Ensure that ethical principles, in particular the principles of 'do no harm' and protecting clients' confidentiality and safety are at the forefront of all reporting
- Establish the key audiences and stakeholders who need reports based on routine monitoring
- Ensure the report is tailored to each audience and their needs, addressing the key questions posed by the organisation, and donors, as relevant to each audience, but based on the same data analysis and interpretations, to avoid duplication of effort.
- Ensure that reports are made accessible in various formats to facilitate dissemination, discussion and engagement of all staff across the organisation (e.g. using leaflets, summary reports, presentations, discussion groups)

- Ensure that reporting is conducted by those with appropriate knowledge, experience and competency in research methods, good knowledge and understanding of rehabilitation services and competency in quality enhancement processes.
- Establish the timing and frequency of reporting, to avoid duplication of effort and inefficient use of available resources in the organisation, in terms of staff time.
- Establish at the outset what should be included in a report for which audience, noting the need for raw data, evidence of data analysis, recommendations, implications of findings, actions required and urgency etc.

6.22 Identifying change and action

Routine monitoring reports which report on findings should address the questions agreed by the organisation, noting the standards agreed and current practice. Reports can highlight gaps, shortcomings and areas for improvement, making recommendations with an indication, where possible, as to what may require urgent attention and reasons why. For example, certain practices, or their omission (e.g. absence of risk assessments for clients who may be deemed vulnerable) can constitute serious ethical and professional breaches which can compromise the safety of clients. Routine monitoring reports may highlight not just what current practices and data recording practices are in relation to risk assessment, but also possible explanations, including the lack of appropriate training for staff, lack of clear questions in monitoring tools to identify risk of harm etc. The urgency of recommended actions can also be noted in reports, particularly for issues posing threats to client safety and well-being.

Formulating the actions required following routine monitoring reports is a crucial component of the quality cycle for it juxtaposes the questions 'what are we doing?', 'what should we be doing?' and 'what should we do to make improvements?' The process of agreeing actions may require extensive engagement with senior managers, particularly those responsible for ensuring high quality rehabilitation services, and practitioners and other relevant staff (e.g. if the actions pertain to addressing difficulties or changes in data entry, or data recording practices).

Key questions
- How will reports be reviewed and appraised, by whom, when?
- What needs to change to make improvements? Actions required?
- Who will do what? How? By when?

Good practice includes:
- Ensure a mechanism for reports to be reviewed, discussed and appraised by all relevant parties, including senior management and those responsible for ensuring the quality of rehabilitation services.
- Ensure reports on routine monitoring identify actions needed and their urgency.

6.23 Implementation

Implementation is a key component of the routine monitoring cycle and refers to the implementation of the changes agreed as a result of the routine monitoring findings. In this sense, routine monitoring has the potential to be a central tool in improving rehabilitation services, but only if the aims and quality cycle are understood by all staff and if actions agreed are implemented. Documenting every stage of the process of decision-making about what needs to change or be improved and why is important to establish a record and transparency about decision-making. It also provides an institutional record of knowledge and practices when there is turnover of staff.

Key question
- How will actions implemented be monitored to ensure accountability?

Good practice includes:
- Establish a process for ensuring that actions are carried out, as recommended and agreed by relevant managers, and within agreed time limits, specifying who is responsible, and subsequently monitored.

6.24 Review and follow-up

Actions agreed need also to be monitored, to ensure that changes decided are not only implemented but subsequently monitored and, wherever necessary, reviewed to see if improvements have been made and standards maintained. Reflection on the implications of the findings for future monitoring can focus on changes needed in service practices, data entry practices, data collection methods, changes necessary to monitoring tools and changes which need to be made to the questions asked in future routine monitoring, ethical considerations etc.

Key questions
- By whom, how and when should the progress of action to be implemented be reviewed to see if it made any difference?
- What needs to be changed in future routine monitoring? Do the relevant standards and indicators need to be better defined? Who should be consulted (colleagues, clients etc.)? Should the monitoring tools or methods be revised and how?

Good practice includes:
- Ensure a process which ensures formal review and which allows reflection on what difference any actions and improvements have made, and what are the implications for future routine monitoring.

6.25 Repeating

A routine monitoring process as part of a quality cycle necessitates regular repetition to continually improve services and practices. Organisations will decide, subject to their priorities and resource availability, the frequency of repeated monitoring of all client information relating to rehabilitation services.

Improving the routine monitoring process involves more than simply repeating the same process every year or more frequently, if necessary changes to the process have not been made. Reflecting on and identifying any changes, for instance with data collection, data storage, analysis or reporting, can help establish what needs to change in the process, to ensure the routine monitoring process is less time-consuming and wasteful in resources.

Key questions:
- Returning to the questions: what are we trying to achieve?
- What changes are needed to repeat the monitoring process next time (e.g. in monitoring tools, methods of analysis etc.)
- When should routine monitoring be repeated?

Good practice includes:
- Ensuring that routine monitoring is repeated at appropriate intervals
- Ensuring that changes are made to the routine monitoring process, where necessary, to

facilitate future monitoring
- Establish a protocol for repeating routine monitoring, subject to necessary changes made to improve the process and make it more efficient and meaningful.

6.26 Indicators of an effective monitoring systems

An effective monitoring system is one which is safe, secure, and meets the organisational needs for routine client-related information which can help inform rehabilitative practice, service quality initiatives, service development and strategic planning.

More specifically, a successful routine monitoring system ensures the availability of:
- Comprehensive information on the rehabilitation services' activity levels
- Comprehensive information on specific questions relating to client demographics, client needs, clients' experiences of torture and other ill treatment
- Information and regular feedback about trends and changes in client population, their experiences of torture, needs etc. as well as changes in civil society/state services in including or excluding torture survivors
- Information on clients from specific groups (e.g. from certain countries, ethnicities, sexuality, torture experiences) as requested/required by the organisation
- Information and periodic reports on trends and changes in the services and interventions provided
- Information and periodic reports on average duration of care/treatment for clients (e.g. aggregated by age, gender, torture experiences etc.)
- Certain information only with authorised access for specified individuals (e.g. information relating to interventions provided in a specific service/ team; or assessment and referral practices within one component of services/team).
- Information which systematically identifies areas for improvement in clinical practices/ services, changes required and monitoring of any changes implemented.
- Information of what is being achieved by services, against set standards and what needs further improvement to achieve those standards.

A summary of steps in implementing an effective monitoring system is found in Figure 6.

Understand Monitoring	• Establish a shared understanding of monitoring • Agree on type of monitoring needed and achievable • Monitoring as a continuous cycle • Establish a system of monitoring before starting the process

Resources and skills	• Allocate resources • Agree roles and responsibilities • Engage staff and all management

Standards and benchmarks	• Agree standards and benchmarks • Define type of monitoring that best addresses organisational needs/resources • Define questions and information required

Data required	• Identify minimum data set • Design approach and system of data collection • Identify monitoring tools

Data collection	• Identify skills and knowledge required for data collection • Design efficient method for data collection • Regulate data storage and retrieval

Analysis	• Agree method of analysis • Identify skills required for analysis • Explore all possible explanations for results • Acknowledge limitations

Dissemination	• Identify relevant audiences • Identify methods to report to diverse audiences • Report the changes and actions required

Follow-up and improvement	• Implement emerging and agreed actions • Review the changes and follow-up implementation • Identify ways to improve monitoring process

Figure 6: Implementing an effective monitoring system

6.27 Clinical audit projects

Clinical audit projects, as mentioned earlier, are another method of monitoring. Clinical audit projects focus on specific aspects of service delivery, sometimes on whole services, sometimes on a specific service. Such projects are designed to address specific questions, related to particular standards of rehabilitation services, as illustrated below.

The audit cycle is similar to the routine monitoring cycle for rehabilitation services, with similar steps:

Step 1: Standards need to be agreed and as clearly defined as possible, reflecting the service model and goals, as well as meeting legal and professional obligations. The key question is 'what are we trying to achieve?'

Standards should ideally address legal and/or clinical standards as outlined in Section 3. For example, the legal standard for rehabilitation which requires there to be early identification of torture survivors also fits with professional standards to offer timely care to those in need and particularly to those considered most vulnerable.

While the standard of early identification may seem as if it has the same meaning and same indicators in different settings, in fact each rehabilitation service may interpret this particular standard differently. For example, the standard of early identification of torture survivors requires different procedures in different service models within different contexts.

A community-based model of service delivery which provides assessment and care in the community, and within refugee camps, may define early identification as an obligation which requires all refugees in refugee camps, for example, during humanitarian crises involving mass human rights violations, to be assessed within 4 weeks, within the camps. In a service model where rehabilitation services operate within state-provided healthcare settings, early identification may mean that initial assessments are conducted within other clinics, to ensure early identification; or that frontline health professional staff in primary health care settings, detention centres and in hospital emergency services are trained and supervised by those specialising in working with torture survivors, to conduct brief screenings to improve the identification of torture survivors, as early as possible.

Each service then has to clarify exactly what a particular standard means in their context and service setting.

Step 2: Standards need to be carefully articulated, measureable and meaningful in relation to the service model. Using the example of the standard of early identification of torture survivors, one service could elaborate this further within their service model as described below:

Standard: Early identification of torture survivors
(a) All refugees in the refugee camps will be systematically assessed with an initial assessment conducted for each adult individual, within each household, within one month of arrival in the camp.
(b) All initial assessments or screenings will be conducted by trained health professionals, within the temporary home of the refugee person.
(c) All those identified as torture survivors during these screenings will be referred within 2 working days for specialist assessment in the torture rehabilitation centre.

(d) All urgent cases where there is an immediate risk of suicide, harm to self or others, or child protection concerns will be referred immediately, within the same working day to designated services.

(e) All initial assessments and referrals will be documented in relevant monitoring tools (assessment and referral forms as specified by the service).

(f) All completed assessment and referral forms will be placed within confidential client files held at (name of office location or venue).

To monitor whether the service standard is being adhered to, the service has to not only define the standard but articulate what obligations it places on relevant staff in terms of their practice – in other words, what should staff be doing to achieve the standard set.

Step 3: Consulting clients or 'service users' to define topics for auditing is considered good practice. This process can include discussions between staff, managers and service users and other stakeholders. Findings from service evaluations (see Section 7), from client complaints, critical incidents, feedback clients provide etc., can all be used to decide audit topics. Defining the audit topic should be followed by a clear articulation of the audit question – what exactly is the question being asked of the current service? Which aspect of a service standard is under scrutiny?

Step 4: Designing an audit project based on an audit topic, and more specifically, on an audit question is the next step. An audit project design should specify the key question under review, the client sample and the time period of sampling. Designing an audit project includes developing audit monitoring tools (see Appendix 3 for examples), with the standard of early identification, to sample assessments conducted during a specified time period and to assess the extent to which these standards are adhered to. So, the standard of an initial screening assessment to take place within 4 weeks of arrival in a refugee camp can be assessed by establishing date of arrival and date of the initial assessment, and calculating what percentage of assessments in a specified time period meet this standard.

Step 5: Implementation: Having designed an audit project, the next stage is to implement it. The process of implementation requires collective effort and staff engagement.

Step 6: Collating data and analysis: The findings from the implementation stage need to be collated and analysed, according to the audit project design. The method of analysis should be appropriate to the audit question asked and agreed at the outset since it can influence the sampling method and time period of data collection. Analysis may involve a range of methods, qualitative and quantitative, though it is more common to use numerical data in audit projects which allows quantitative analysis. Quantitative analysis can range from percentages to advanced statistical analysis. It is preferable to keep analysis simple as possible, so that all those involved in rehabilitation can also easily understand the findings.

Step 7: Report preparation: An audit report should then be prepared to summarise findings for dissemination and discussion across the relevant staff groups in the organisation. Again, the audit report should be simple, presenting findings in clear ways, using simple graphs if appropriate, and reports should be easy to understand by all staff involved in rehabilitation. For an example of an audit report template see Appendix 3.

Step 8: Comparison is an important next stage of the audit cycle. This involves comparing the findings, 'what are we doing?', with the standard, asking 'how well are we doing, according to what

we set out to do?'. This process involves appraising the findings, exploring possible explanations for any discrepancies between the findings and the standard. This process of discussion and reflection should involve all staff discussing the findings widely and together. Staff may reflect on difficulties in the audit monitoring tool used, the sampling, the clarity of indicators, professional practice, administration procedures etc.

Step 9: Action plan: The next stage of the audit cycle is the establishment of an action plan (see Appendix 3 for an action plan template) to specify what needs to change and which improvements need to be made to better meet the standard of early identification. This process would involve extensive discussion, reflection and consultation before decisions are made as to required actions and improvements. Action plans should take a systematic approach, considering all contextual factors (internal and external to the organisation) which may impact on actions, and specify time limits and who is responsible. There should be a process agreed to monitor the implementation of the action plan.

Step 10: Implementation of action plan: The implementation of the action plan is the next stage, with ongoing reflection on the method of audit, the appropriateness of the audit tools used, organisational processes and staff engagement etc. It is important to remember that implementing an action plan is not a simple matter of carrying out actions, but a process which involves organisational change and changes in people, in staff behaviour and practices. This requires considerable management skill and sensitivity, recognising that rehabilitation services are delivered by staff from different professional backgrounds with differing professional socialisation, practices, and priorities, as well as differing types and levels of knowledge, experience and skills. Inter-professional rivalry and conflict, inter-team competition and conflict, can also derail an action plan, however robust. Managing change requires attention to the process of change and engaging and supporting staff in the change process, identifying training needs for different staff where necessary for improvements in rehabilitation services.

Step 11: Repeating the process. Finally, the audit project may be repeated at a later stage, after changes have been made, to again see to what extent current practice meets agreed standards, and to ensure that changes and improvements can be sustained.

The cycle of ongoing monitoring and improvement can then continue with services striving to meet standards, and standards and practices being refined to ensure high quality rehabilitation services. Essentially, audit projects need to be specific about the standards being monitored, realistic, meaningful, ethical, and to engage staff in a collaborative, collective effort throughout the service. Examples of audit questions can be found in Box 7.

Box 7: Examples of audit questions and projects for rehabilitation services

- Are all clinical records documented in designated client files, within one day of the client assessment being completed? If not, what are the reasons?
- Are all clients referred to the rehabilitation service given an appointment within two days of the referral being received? If not, what are the reasons?
- For clients assessed as being at risk (of suicide, self-harm, harm to others or child protection concerns raised), are clients referred for urgent assessment by designated staff within 24 hours?
- Are all client assessments followed by a case discussion and review by a multidisciplinary team within two weeks?
- Are all clients informed in writing (in their own language) and verbally (with interpreters where necessary) of the organisational policy to uphold confidentiality in all aspects of their rehabilitation care, with the limits to confidentiality explained? Is consent to receive services and interventions obtained (in their own language) before they are administered?
- Are all relevant protocols for computerised data entry by practitioners followed by clinical and legal staff?
- Are administrative processes, such as making and changing appointments, equitable and accessible to all clients (including where the language needs of a client require an interpreter)?
- Are phone call requests for information sharing about clients handled consistently with confidentiality and data protection?

6.28 Summary

Monitoring is a central tool in improving and maintaining quality standards of torture rehabilitation services. It can involve routine monitoring, which may include routine clinical outcome monitoring (see Section 8), as well as specific audit projects. Monitoring is a serious endeavour which cannot be undertaken lightly. To do so is not only counterproductive, as it can alienate staff and destroy goodwill in an organisation, but also risks being tokenistic. Where monitoring is carried out by those lacking in necessary knowledge and skills, it is likely to lead to poor practice. Monitoring practices in an organisation which impact adversely on client care or hinder the delivery of quality rehabilitation services can also be considered unethical.

There are many barriers to effective monitoring, summarised in Box 8.

Box 8: Common barriers to effective monitoring

- Lack of adequate (ring-fenced) resources for monitoring systems
- Lack of expertise (knowledge, skills and experience) in research methods, including project design and analysis, database and information systems
- Lack of an overall strategy for monitoring
- Lack of clear plans for which audit projects are needed
- Lack of clarity on service model and service goals
- Lack of awareness, or understanding, of rehabilitation standards, including professional and legal obligations
- Lack of professional respect for and understanding of cultural or other differences between service providers and torture survivors, differences which have a bearing on what is monitored, how, using which tools
- Lack of awareness, or understanding of rehabilitation practices and processes between practitioners from different professional backgrounds and by managers
- Poor relationships between professional groups, within teams or within the organisation
- Lack of staff engagement
- Lack of management understanding of monitoring and change processes
- Lack of management engagement and commitment to monitoring
- Lack of effective leadership, project management, overall organisational management and skills in change management
- Poor relationship between practitioners and managers
- Lack of integration of monitoring within the daily work of staff
- Fear of workloads increasing, of punishment, or of other adverse consequences for individual staff or professional groups
- Organisational culture which is critical, blame-focused, internally competitive (e.g. for resources, or 'who knows best', who is the most skilled etc.), unsupportive, driven by fear of punishment and criticism, which objectifies staff and clients and does not acknowledge successes, good practice, effort and goodwill amongst staff.

In summary, as with all forms of monitoring and evaluation, staff engagement, collective effort and effective leadership are essential. A supportive environment is also vital, an environment where there is encouragement of and positive feedback to staff, as well as an approach which fosters ownership across the organisation of the goal of improving and maintaining the standards of rehabilitation. A management approach not overly critical and punitive, but inspiring, supportive and nurturing the spirit of collaboration and collective effort, is central to the success of all monitoring, including audit projects. Finally, it is essential that the organisation, and donors, dedicate resources to ensure that there are effective and ethical monitoring systems in place, implemented by those with the appropriate level of knowledge, skills and experience.

7. Overall service evaluation

Conducting service evaluations is the focus of this section. Different methods and the challenges involved in conducting service evaluations are outlined, with examples of service evaluation designs which address key quality criteria and established standards for rehabilitation services for torture survivors.

7.1 Defining evaluation

Definition: Evaluation is the systematic assessment of a practice, activity, project or service to establish its effectiveness. It involves the measurement of the effects (impact and outcomes) or processes of a service or intervention, and the interpretation of findings.

Evaluation is a complicated process and includes a wide range of concepts, approaches and methods. It requires different levels of knowledge, skills and different types of tools, depending on what the evaluation questions are. Evaluation for rehabilitation services can be:

- **Front-end:** Focusing on assessment of needs and context and conducting a feasibility analysis to provide guidance on how a service should be designed and delivered, before implementation
- **Formative:** Focusing on the development and the process of implementation of a service, project or programme which provides information on what changes need to be made to the service, project or programme design, delivery or management
- **Summative:** Focusing on the impact of service, project, activity or programme by identifying outputs and outcomes, assessing whether specific objectives have been met and to what level, often to make decisions about the continuation, reduction or expansion of a service, project and funding. Summative evaluations may also consider intended and unintended or unexpected outcomes, and may lead to the development of future services or programmes – in which case they can also have a formative function.
- **Systems analysis:** Focusing on various systems and policies and the measurement of inputs, outputs, changes achieved, effectiveness and efficiency
- **Service evaluation:** Establishing the quality of services and whether they meet required standards. Identifying any failings or shortcomings requiring action.
- **Project or programme evaluation:** evaluating the delivery and impact of a project or programme (e.g. a project providing services such as 'vocational integration and support service') according to targets and milestones agreed with donors.

Definition of service evaluations: Service evaluations are large- or small-scale projects which assess particular services, or aspects of a service, according to agreed standards and quality criteria (e.g. appropriateness, accessibility, impact, equity, sustainability).

Questions which service evaluations address are summarised in Box 9.

Outcomes and outputs:

Service evaluations can combine the measurement of outputs and outcomes. Service evaluations, like routine monitoring and audit, are a means of ensuring quality services, and a tool in improving services and in planning and developing new services.

Outcome measurement in health and social care service delivery organisations include a wide range of methods, each with particular, and some very sophisticated measurement tools. Donors and service providers often focus only on 'clinical/treatment outcomes', though other outcomes are important to assess the quality of services which are typically diverse, and not just 'treatment'. Service evaluations may measure:

- Output indicators, for example:
  Number of referrals made to and accepted by a service
  Number of clients who take up a service offered
  Number of clients who miss (DNA) their appointments without reason
  Number of clients who decline services offered
  Number of clients who drop out of services/have unplanned endings)
  Types of clients/backgrounds who take up a service and those who do not
  Number of sessions attended on average by clients
  Length of treatment/care in a particular service

- Outcomes could include changes such as progress of clients, benefits, learning or other effects that result from the service, project or activities which the organisation provides. Outcomes can be:
  Final outcomes which are changes that are assessed at the end of the intervention, service or activity
  Intermediate outcomes which are changes that happen as steps along the way to what may be

seen as the main, intended outcomes or goals

- Outcomes could include:
  Clinical outcomes (e.g. changes in trauma symptoms, sleep disturbance, mood)
  Process outcomes (e.g. role of therapeutic relationship in outcome, role of relationship with
  interpreter in outcome)
  Interpersonal relationships outcomes (e.g. changes in marital relationship, family relationship,
  parenting relationship)
  Function outcomes (e.g. functioning in employment, education, family obligations and other
  important areas of living)
  Context outcomes (e.g. changes in legal status, housing status, employment status)

7.2 Types of service evaluation

The term service evaluation is often misunderstood as constituting only clinical outcome
evaluation (see Section 8). However, it also includes diverse questions relating to the quality of
a service, such as adhering to agreed quality criteria and standards for torture rehabilitation
services. Broadly speaking, service evaluation addresses the questions 'how well does a service
work?' and 'what is the quality of a service?'. Like routine monitoring and audit projects, it is a tool
in ensuring quality services, in improving services and in planning and developing new services.

Types of service-related evaluation include:
- **Overall service evaluation:** Evaluation of overall quality of a service according to agreed
  standards and quality criteria for torture rehabilitation services
- **Clinical outcome evaluation:** Focusing on the systematic measurement of the effectiveness
  of specific interventions, activities or therapies by measuring changes (nature, quantum and
  clinical significance) in specific outcomes (e.g. mood, symptoms, functioning), ensuring the
  exclusion of all other possible biases and explanations for any identified changes following
  interventions
- **Routine clinical outcome evaluation:** Providing systematic, ongoing measurement of positive
  or negative changes on specific dimensions or variables (e.g. symptoms, functioning) for all
  clients, on a routine basis at specified intervals (e.g. every session, monthly, three-monthly, at
  the end of particular treatment or service/at discharge etc.)
- **Process outcome evaluation:** Evaluating the process that influences treatment, care and
  clinical outcomes (e.g. process of therapeutic relationship, multidisciplinary team-working
  and joint care-planning and impact on clinical outcomes, on clients' own reports of outcomes
  and experiences of treatment and care). Focusing on 'how' rather than 'what' — 'how much'
  a service or intervention or activity influences the outcome. This can also address general
  questions of 'what is going on?' or 'how is the intervention/service progressing or working?'

Process or clinical outcome evaluation targeted at specific services or client groups:
Focusing on assessing the impact, effectiveness and process of a particular service (e.g. children
and family services) or service component (e.g. group art therapy) with a particular client group
(e.g. with young people aged 18-25) based on particular clinical and process outcomes

7.3 Evaluation cycle

Evaluation, as a process for ensuring ongoing improvement of rehabilitation services, involves several cyclical stages (figure 7):

- **Evaluation question:** Agreeing what the evaluation question is and what standards it focuses on
- **Outcomes and outputs:** Agreeing what outcomes and outputs are to be assessed
- **Designing an evaluation project:** What are we going to look at, how and with which clients, receiving which services/in which area of the service etc.?
- **Evaluation tools:** Select appropriate measurement tools
- **Population/sample:** Select and recruit the population to invited to participate in the evaluation research
- **Collect data:** Who should collect data, when, how, for what period, with what safeguards etc.?
- **Collate data:** How shall we put together all the data we have collected? In what format?
- **Analyse data:** How shall we analyse the data? Who will do the analysis?
- **Interpret the analyses:** What do our data mean? What do they tell us? Who will interpret the results?
- **Identifying change and action:** What needs to change to make improvements in future evaluation research, and in services? What needs to change in the methods used, the tools used, the conceptual basis, the service evaluated, clients who participate etc.? Who will do what? How? How will such findings and their interpretation be disseminated?
- **Implementation:** Make the changes agreed.
- **Review, reflect, and repeat:** Did the changes make any difference? How? Do we need to evaluate again? With which client population, which service, which component, when etc.? Do we need to revise our methods, services, interventions? Do we need to identify other or different outputs and outcomes? Going back to the beginning, ask how effective is our service, intervention or activity in achieving the outcomes intended?

Ask questions

Design and implement projects to answer questions

Analyse and interpret results from projects

Identify areas to change/improve

Reflect and implement change
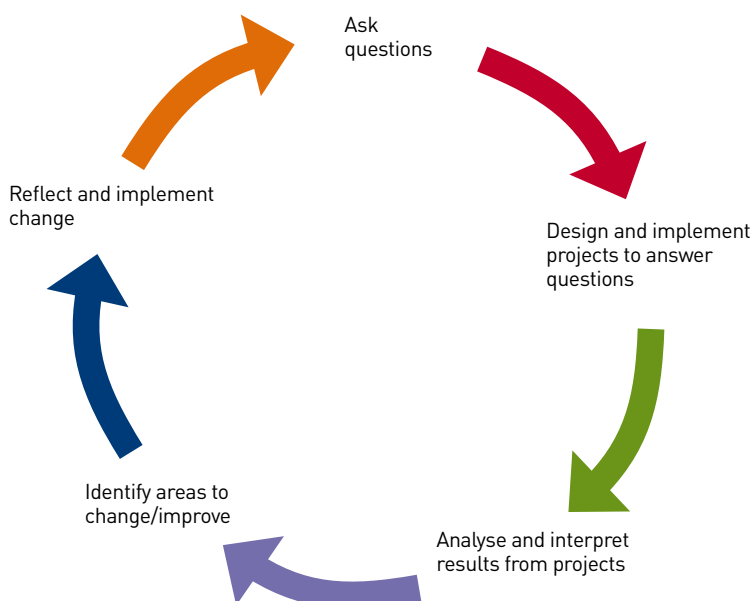
Figure 7: Cycle of evaluation

Conducting evaluations requires knowledge of the range of types and methods, and of how suitable they are to the evaluation question. It is tempting to do evaluations which are quick and one-off, requiring as little time as possible, but there is a risk that, without proper attention to method, to the quality of data collection, process and the cycle of evaluation, the evaluation will be little more than impressionistic or a 'guestimate', at worst an attempt to distract from weaknesses or any negative feedback which otherwise could be useful to better understand and improve services. Furthermore, conducting quick and shoddy evaluations which lack rigour and integrity is unethical, given the effort and energy it requires from clients, and also wasteful of time, resources and goodwill from staff.

It is well-established in the health and social care fields that unless evaluations and feedback from them are used effectively to make changes and to improve services, and integrated in the organisational culture and practices, that they are tokenistic and wasteful activities unlikely to lead to improvement of services. In short, conducting evaluations is a complex and time-consuming process, and if it cannot be done with an appropriate level of knowledge, skill and ethical practice, with effective use of feedback from evaluations within the organisation, there is a case for not doing it at all until appropriate foundations are established.

That said, all organisations should aim, at minimum, to establish systems for monitoring and evaluation, starting with small-scale evaluations, with simple feasible designs, ethically and methodologically sound. Organisations can all develop a strategy for a programme of monitoring and evaluation, refining systems, tools and methods used over time.

Good practice includes:
- At minimum, to establish a system for evaluation
- At minimum, to start small-scale evaluations
- At minimum, to develop a strategy for developing, refining and integrating monitoring and evaluation systems and activities
- At minimum, ensuring that feedback from service evaluations is carefully considered and used by the organisation

Criteria which should be met before evaluations are undertaken are summarised in Box 10:

Box 10: Criteria for conducting service evaluations

- **Structure and commitment:** Organisational and management structures, systems and commitment to service quality monitoring and improvement
- **Utility:** High likelihood that findings from evaluations will be useful to, and will be used by the organisation
- **Integrity:** Structures and systems in place to ensure that evaluations will be conducted ethically, professionally and with high regard to client safety and well-being throughout the process
- **Feasibility:** An environment, internal and external, where evaluations can be safely, practically and effectively carried out without harm to clients, staff or others, and without compromising the care provided to clients
- **Competency:** Appropriate level of knowledge, skills and experience to carry out service evaluations professionally, ethically and competently, with full understanding of the possible risks of conducting such evaluations in politically sensitive and unstable environments

7.4 Competency in conducting evaluations

Conducting evaluations requires competency in many areas, depending on the nature of evaluations, as summarised in Box 11 below. However, not all organisations have staff with the relevant competencies. Management decisions may need to be made about what is feasible and where relevant expertise can be sought externally either to support and supervise appropriately qualified, though junior, staff, in conducting evaluations, or to conduct evaluations on behalf of the organisation.

Box 11: Competencies in conducting service evaluations

- Skills in clarifying the purposes of the evaluation
- Skills in establishing which type of evaluation is required
- Skills in identifying staff, skills needed in a team or organisation to implement evaluations
- Skills in evaluation project design
- Skills in identifying the most appropriate methodology
- Skills in a range of research methods, analysis and interpretation (qualitative and quantitative methods)
- Skills in understanding and managing complex data
- Skills in inter-cultural evaluation
- Skills in conducting evaluation projects and research activities with interpreters, where necessary
- Skills in conducting evaluations with vulnerable populations such as torture survivors
- Skills in reporting on evaluation findings and articulating recommendations
- Skills in facilitating organisational engagement, commitment and utilisation of findings
- Skills in understanding and working within complex and politically sensitive, unstable and or unsafe contexts

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There are many advantages and disadvantages of seeking competency within the organisation or externally, from consultants, academic institutions etc. These are summarised in Box 12 below.

The benefits of seeking external expertise to supervise staff and as consultants to the organisation are that staff knowledge and skills can be enhanced and capacity to do future evaluations in-house be increased. This ensures a cycle of evaluations that are integrated and embedded in organisational structures and practices. A major strength of in-house evaluations with external consultation and support is that staff have intimate knowledge and understanding of the nature and complexity of rehabilitation for torture survivors, and of the organisation's goals and service model. This is central to designing and implementing appropriate evaluations. They can also share particular insights based on their knowledge of the organisation and of rehabilitation practices and approaches, for instance their clinical experience. This can facilitate the design of evaluation projects, recruiting participants, considering ethical aspects, as well as offering useful reflections on the analysis and interpretation, based on their own understanding of rehabilitation work.

The disadvantage of using in-house practitioners who may also be interested in evaluation research is that, without dedicated time for evaluation-related work, the research tasks involved are likely to suffer and lose priority over other more pressing commitments, such as clinical work. Additionally, staff interested in leading, conducting or engaging in evaluation projects may lack

the necessary expertise. This can be difficult to confront where staff are not aware of the gaps or limitations in their knowledge and skills to do these. The enthusiasm to engage in evaluation can be harnessed by encouraging staff members to work with other more experienced practitioner/researchers, where available and appropriate. Where this is not possible, it is poor practice to give a novice or unqualified staff member the task of conducting evaluation projects, given the possibility of ethical breaches and of risks to the integrity of the evaluation process.

Box 12 Advantages and disadvantages of 'in-house researchers'

Advantages
- Developing skills and knowledge in-house, where consultancy and supervision are available
- Developing capacity and thereby increasing sustainability of evaluation practices within the organisation
- Intimate knowledge, understanding and experience of rehabilitation practices with torture survivors and organisational goals

Disadvantages
- Lack of dedicated, protected time
- Lack of necessary expertise: knowledge, skills, experience, qualifications
- Lack of availability of external support (consultancy/supervision)
- Pressures on time to prioritise other daily commitments
- Risk of, or openness to, accusations of bias (especially where there is a lack of rigour and transparency of data collection and analysis)

Good practice includes:
- Ensuring that those conducting evaluation are competent to do so
- Ensuring that those conducting evaluation are provided with the necessary management support and technical supervision required for ethical and professional practice

7.5 Approaches to seeking feedback on services

There are various approaches to obtaining feedback on services provided. Some of these are thought of as evaluation but, strictly speaking, they are not, although they provide useful information. For example, clients' satisfaction questionnaires, clients' complaints, or stakeholders' views of services or of referral pathways can all provide feedback, but they are not sufficient as evaluations. By definition, evaluation projects of services are largely thought of as research. However, there are other approaches, such as outcomes mapping, used in reflecting on and identifying good practice in for example rehabilitation services for torture survivors, which can be described as a form of whole systems and service evaluation.[4]

That does not mean that, in the absence of service evaluation research, it is not helpful to seek other forms of feedback. Satisfaction surveys, feedback from referrers, clients and other stakeholders are all useful, but not a substitute for service evaluation which adopts a more formal methodology. With regards to satisfaction surveys, while it is important to ask clients for feedback, there is too little attention to how this is done and at what time point. Asking generic questions about satisfaction at the point of completing may elicit answers which represent gratitude to the therapists involved, particularly if the questions are presented by the treating therapists. Specific questions about how the service was delivered, whether it met initial expectations and hopes,

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4 For further reading, see Bittenbinder, E. (ed.) (2012) Beyond statistics: Sharing, learning, developing good practice in the care of victims of torture. Von Loeper Literaturverlag: Berlin.

and to what extent problems presented at the outset have been resolved, asked a month or more after discharge may give a more nuanced and useful account. Particular attention should be paid to ensuring confidentiality and to segregating the seeking of feedback from the provision of care.

Differences between clinical outcome evaluation and satisfaction with the service are discussed in Section 8. It is important to note, however, that there is often only a weak relationship between the two. This is for two main reasons. At the end of a service, satisfaction questions often elicit answers which are related more to gratitude (as described above) than to satisfaction with outcomes. Furthermore, clients' expectations are often fluid across time, changing with exposure to treatment, and the relative weightings of the extents to which these expectations have been met are not represented well in a single measure of satisfaction which is anyway liable to change with further reflection and with external events. For these reasons, satisfaction is not a useful key measure of service outcome.

7.6 Defining service evaluation questions

Central to any service evaluation is clarity on what exactly is being asked: what is the service evaluation question? It is the nature of the evaluation question which will determine the project design and feasibility.

Service evaluation questions can be exploratory or specific but, ideally, should relate to agreed standards and quality criteria for a rehabilitation service. Service evaluation questions should also fit the service model: that is, questions should make sense for the service design and the services offered by any particular organisation (see Section 5).

Questions can focus on the whole service, for example where the organisation and service is small, comprising one team (e.g. a multidisciplinary team working with adult torture survivors). Questions can also be focused on one particular service (e.g. family service, a social welfare/advice service); a particular intervention/ therapeutic approach (e.g. art-based therapeutic groups); or on a collection of services received by a particular group of clients (e.g. services for young people between 14-17 years; services for torture survivors who are young mothers; services for women who have been raped); or on a particular intervention/therapeutic activity for a particular client group (e.g. relaxation group for men; music therapy for children).

Service evaluation questions can also explore standards related to the service design. For example, in any given national context (e.g. in a country undergoing transition and where the fear of being identified as a torture survivor may incur further risks of harm and shame), how appropriate is a design which provides rehabilitation from a specialist team which is however located within the state health service (e.g. a general hospital)?

Similarly, service evaluation questions can focus on any aspect of the design of a service and standards defined by that service. For example, with the standard of providing prompt services based on early identification, evaluation questions may be 'how prompt are referrals to relevant medical services (state/other) made for torture survivors identified as having medical needs related to torture?'; or in services which provide community screening 'how promptly are those identified as torture survivors referred to specialist rehabilitation services'; or in services where all those referred are given a thorough assessment and torture survivors identified, 'how promptly are clients provided with rehabilitation care, once accepted as a client by the service?' The latter, for example, could relate to a specific service standard which states that clients should not wait more than four weeks from assessment to commencing rehabilitation treatment or care; or more

than one week if cases are deemed urgent. Related service evaluation questions may be 'how do clients experience the wait between assessment and being offered ongoing rehabilitation care?'; 'what is the impact on family members of torture survivors of waiting for periods beyond four weeks for rehabilitation services to commence?'.

Service evaluation questions may address more than one standard (e.g. accessibility and impact of family services for families where one or more members has experienced or witnessed torture). Service evaluation questions can also address more than one standard for a specific intervention/ therapeutic activity (e.g. appropriateness and effectiveness of sports-based groups for adolescent boys aged 13-18).

Service evaluation research examining a particular intervention tends to require rigorous research methodology if the aim is to exclude all other possible variables and explanations which may contribute to the changes seen after the intervention. If the intervention being evaluated is entirely novel, or is a 'mainstream' intervention being 'tried out' on a group of torture survivors, there would need to be some ethical scrutiny and approval, particularly with a vulnerable population. If the intervention is routine in the service and offered as part of other interventions, the question may be stated more generally, such as 'what is the impact of this service on those boys' – in which case the methodology adopted would be different, and broader.

For the question: 'Is art therapy effective for women torture survivors who have been raped?', the research design would need to consider carefully factors such as the specific inclusion criteria for the sample, definition of 'rape' to be used, age of women, etc., and whether to exclude all women who had experienced sexual torture which did not involve rape, etc. This process of designing such a project is usually unrealistic in a setting such as a rehabilitation service, where there are many outside factors, including the environment of a torture survivor's life, which may account for improvement or hinder progress. Similarly, some project designs would be unrealistic and unethical in rehabilitation centres if they deny access to some clients – for example, withholding a service, or a particular intervention which is available, to clients who are in need, just because they do not meet specific inclusion criteria for the research project evaluating that intervention or service. Methodological compromises can be made in such situations, but services must be rigorous and diligent in attending to ethical and professional obligations to provide services based on need, and not prioritise evaluation research over meeting clients' needs.

It is essential to understand the service model and overall design, purpose and goals of the organisation's services, in order to clarify possible evaluation questions. The questions generated for evaluation would closely match the service model, and its goals, and the context of the service. Thus, no service evaluation is likely to be identical in design to that of another apparently similar project in another centre in another setting or country. While this can make any meaningful comparison of similar services across different national settings, difficult, service evaluations can be tailored to the questions of relevance to the quality of that particular service, in its context.

Service evaluation questions can be broad, open-ended and exploratory, or specific and closed. They can be 'how', 'why', 'what', 'when', 'who' and 'how much' types of questions. The type of questions asked will dictate the methodology adopted and whether the service evaluation also includes an audit project. Some methodologies will be quantitative, others qualitative, and others will adopt a mixed methods approach. Within each type of methodology (e.g. qualitative), many different methods are available, each suited to specific types of questions. Those designing service evaluation projects should be conversant with different methodologies, or may seek guidance and

technical supervision if they lack sufficient knowledge and competence.

Examples of service evaluation questions can be found in Box 13.

<div style="background-color:#C8102E; color:white; padding:8px; font-weight:bold;">Box 13: Sample service evaluation questions</div>

- **Standard: Accessibility**
  - How accessible is X service to all adult torture survivors?
  - How accessible is Y service to young women who are mothers?

- **Standard: Appropriateness**
  - How appropriate are all rehabilitation services provided to torture survivors in the centre?
  - How do clients experience the services they receive? Are they satisfied that the services are appropriate to all their needs as torture survivors?
  - How do clients rate the services they receive in terms of gender and cultural sensitivity?
  - How appropriate is X service in the specific national and cultural context?

- **Standard: Impact**
  - What is the impact of rehabilitation services on clients?
  - What is the impact of rehabilitation services on carers and families of clients?
  - Is there a wider impact of the rehabilitation services provided, beyond the individual and their family? What is it?
  - What is the impact of offering rehabilitation services (or a specific service, such as assessment in front line primary healthcare settings) on the number and quality of referrals from state services to the specialist rehabilitation service/organisation?

- **Standard: Effectiveness**
  - What is the effectiveness of all rehabilitation services offered to all clients?
  - How effective are community-based, home visits by counsellors as a method of initial assessment in identifying those torture survivors who are most vulnerable?
  - How effective is group-based art therapy for children?
  - How effective is group-based art therapy compared to individual art therapy for children who have been tortured?

Key questions:
- What is the service standard being examined?
- What is the question being asked about the service?
- Is the question related to one specific service, or service component – what is the focus of the evaluation?
- Who is asking and for what purpose?
- What knowledge, skills and resources are available for this project?
- What are the ethical and professional implications of developing a service evaluation based on the question(s) asked?
- What are the implications of the service evaluation question and related project, if implemented, for clients and the services they receive?

Good practice includes:
- Ensuring a good understanding of the specific needs of the client population, the service model and goals
- Consulting widely to agree which service standards need to be assessed
- Ensuring staff are engaged in generating questions they want to ask of the service they provide
- Exploring with staff the reasons for their questions, to better understand concerns, context, professional or other interests
- Encouraging discussion, curiosity and reflection amongst staff about their own service and, wherever possible, sharing a collated list of questions staff have begun to generate themselves
- Ensuring that questions can be realistically addressed in a service evaluation and, if this is unlikely, explaining to staff why during initial discussions, whilst being open to re-wording or revising the questions
- Narrowing the list of questions down to the key evaluation questions, and formulating those questions carefully in a form that can be addressed by a research project – questions should be clear, succinct, feasible and ethical
- Establishing the knowledge, skills and resources required to conduct a research project based on the evaluation questions

7.7 Designing an evaluation research project and proposal

Designing an evaluation research project is the next step after deciding the service evaluation questions to be asked. A key principle in developing a design is that it should follow closely the evaluation research question – in other words, the nature of the question will dictate the design. It is tempting to simply repeat other designs, perhaps used in other organisations or studies, but it is essential that the design fits the particular service model and questions being asked.

Every evaluation research project should be formalised in a proposal providing a clear justification and background information on why the specific question is being asked. The proposal should then provide clear evaluation research questions and detail the design of the project.

The design of an evaluation research project has several crucial components, standard in all designs, and detailed in a project proposal. These are summarised below:

Good practice in proposal-writing for evaluation research projects

Aims of the evaluation research and proposed title
- Ensure the aims of the project are clearly stated
- Ensure a clear proposed title
- Ensure that the aim of the project relates to the needs/problems as identified by the service and that it has the potential to benefit torture survivors

Research question(s)/ hypotheses
- Ensure clearly stated, focused and answerable questions
- Ensure they are relevant to the rehabilitation services provided by the organisation

Organisational goals, mission, strategy
- Ensure the evaluation research proposed is in keeping with the organisation's and the rehabilitation service goals, mission, strategy and priorities

Background information

- Ensure there is adequate background information provided, such as relevant literature and existing knowledge and its appraisal, organisational context, national context, organisational concerns and purpose of the evaluation

Methodology

- Ensure the methodology is clearly stated, described and justified
- Ensure the methodology is the most appropriate for the evaluation research question(s) posed (e.g. quantitative, qualitative, mixed method etc.)
- Ensure the methodology is appropriate for the organisation (given its context, resources (including time), external constraints and pressures, need for and use of interpreters etc.)
- Ensure that the intended sample, its size (numbers of participants), inclusion/exclusion criteria, background details etc. are all specified and based on sound justifications
- Ensure the sampling method and recruitment strategy are explained and justified, including number of participants, how participants will be identified, recruited (via letters, posters, via clinicians etc.), how their informed consent will be sought
- Ensure the tools, measures, questionnaires, interview guides etc. to be used are appropriate to the client population in terms of the language used, validity and reliability of tools, time taken to complete questionnaires etc.
- Ensure the method of data collection is clearly stated, ethical and appropriate, given the service setting, constraints etc. and if participants are torture survivors
- Ensure the method of analysis is clearly stated and justified (how data will be analysed), and appropriate to the method adopted and the aims of the evaluation
- Ensure there is a detailed timetable for the evaluation research and mechanisms for monitoring progress

Sample

- Ensure the method of obtaining research participants is clearly stated, ethical and justified
- Ensure the method of sampling is detailed (e.g. cluster, random, quota)
- Ensure there has been sufficient attention given to issues regarding heterogeneity of sample, language needs, the cultural and political context of conducting evaluations with survivors of torture (if relevant) and with those who are in receipt of rehabilitation services
- Ensure the sample size is appropriate for the proposed research question and for the method proposed
- Ensure inclusion/exclusion criteria, where relevant, are specified with justification
- Ensure that the way potential participants will be informed of the project is specified in the proposal, clear and appropriate to the clients' language, culture etc.
- Ensure there is clarity on how participants will be recruited (directly, via third parties, via clinicians etc.)

Attention to ethical issues

- Ensure that the evaluation project is of relevance and of potential benefit to torture survivors
- Ensure all relevant ethical issues are stated clearly (e.g. safety, risk of harm, risk of distress, confidentiality, informed consent, security of data collected etc.)
- Ensure that the steps to be taken to address each of the ethical considerations identified are clearly outlined
- Ensure that any information leaflet/letters for potential participants, staff and others, consent forms, questionnaires or interview schedules or any tools to be used are provided in the proposal (see Appendix 4 and 5 for examples of participant information sheet and consent

form for adults)
- Ensure that any provisions for medical/psychological/legal aftercare, if needed, are clearly specified
- Ensure that data integrity is considered in detail, outlining how data will be protected, how confidentiality will be ensured etc.; and what will happen to the data collected after the project has been completed

Contribution to knowledge
- Ensure the proposal outlines the potential for contributing to knowledge in the field

Contribution to service development
- Ensure the proposed evaluation research outlines how the outcomes of the project and feedback can be used to improve services for survivors of torture

Implications for resources
- Ensure the resource implications of the proposed project are detailed (staff time, clients' costs of travel etc., cost of interpreters, cost of using licensed tools and measures, administration costs, time required for staff to conduct the project etc.)

Details of collaborators and supervisors
- Ensure that any other proposed/ongoing projects at the organisation which could be developed as joint/collaborative research or which might duplicate efforts are discussed
- Ensure that there are named advisors and supervisors with appropriate knowledge and skills to support and guide the project staff

Details of plans for dissemination and publication
- Ensure the plans for dissemination are detailed (what format, for whom, how, where?)
- Ensure that if the research will be conducted for a university degree, that it is clarified where and how the complete thesis will be available
- Ensure that any plans for publication, intended audiences and possible avenues for publication are outlined

Integration of findings in the organisation
- Ensure that the plans for integrating the findings in the organisation, to complete the quality cycle, are outlined, in agreement with management

Time-table
- Ensure that there is a detailed time-table with clear milestones for monitoring the progress of the project

7.8 Seeking ethical approval
It is essential that all service evaluation research projects which involve human participants (whether torture survivors who are clients, their carers, families, staff, interpreters etc.) undergo independent scrutiny by a formal body competent and authorised to conduct ethical reviews and to grant ethical approval. Ethical approval is a requirement to ensure that the project will not cause harm to participants, and that it adheres to professional and ethical codes of conduct relevant to all health and social care services; and that it complies with national legislation, for example, with regards to safety and confidentiality.

Whilst professional and ethical codes may vary between countries, they all address ethical obligations when conducting any professional or research activities with human participants, including those deemed vulnerable. National laws may differ, for example, as regards data protection, confidentiality, access to health records etc. so it is vital that the responsible ethics approval body is fully conversant with the relevant professional and legal codes. It is also essential that those responsible for designing and implementing evaluation research projects be aware of and understand their legal and professional responsibilities when undertaking projects, whichever institution they are working in and wherever rehabilitation services are provided.

Not all organisations providing rehabilitation to torture survivors will have access to ethical approval bodies. Some may have additional regulations to abide by if, for example, the service is located within, or as part of, state health or social care services. Some rehabilitation services may function as part of, or be attached to, an NGO whose primary remit is not rehabilitation for torture survivors. Any evaluation research activities in these types of services are also bound by professional and legal codes, and equally require ethical approval by a body authorised to do so.

Where possible, ethical approval mechanisms within academic institutions (e.g. universities) or within state services (where appropriate) can be utilised. No evaluation research project should commence without formal ethical approval being granted – to do so may breach legal, professional and organisational codes.

Since obtaining ethical approval will take time, it is helpful to review ethical considerations as early as possible in the proposal preparation, seeking appropriate supervision wherever necessary, and to apply for ethical approval at the earliest opportunity, once the proposal is completed. It is helpful to factor in the time approval may take in the specific national and local context and to take this into account in the time-schedule in the proposal.

Good practice includes:
- Ensure that, for all service evaluation research, ethical approval be sought from a committee/body competent and authorised to grant this
- Ensure that professional and technical research supervision is sought, where necessary, to ensure that the proposal has outlined all ethical considerations and detailed how these will be addressed
- Ensure that no service evaluation research projects commence before ethical approval is granted

7.9 Implementation
As with monitoring (Section 6), after designing the project, including choosing the sample, the method, the tools and the method of analysis, the next step is the implementation. This will closely follow the steps noted within the proposal. The process of implementation would include consultation and engagement with staff, data collection, data collation, data analysis and interpretation of findings. The process of implementation requires competencies in project management and in research methods. It cannot be done half-heartedly without risking harm to clients, damaging staff relationships and morale, and without seriously undermining the organisation's monitoring and evaluation systems and strategy.

Good practice includes:
- Ensuring ethical and professional practice throughout the implementation of the service evaluation research project

- Ensuring the design of the project is followed carefully and, where significant changes are proposed, that consultation/technical supervision is obtained and ethical approval is sought
- Ensuring that those implementing the service evaluation research are competent to do so, with appropriate levels of knowledge and skills in research methods

7.10 Reporting on service evaluation

Reporting on findings from service evaluation projects will depend on the requirements of the organisation but, at the very least, a project report should use the project proposal as a framework for explaining the aims, the key service evaluation question and related service standards, the methodology, the results, the interpretation and discussion of those results and implications of the outcome of the evaluation project. A project report should outline key recommendations as preliminary steps for wider dissemination, reflection and discussion in the organisation.

Good practice includes:
- Preparing a report on the service evaluation project
- Ensuring the project report addresses the service evaluation question on which the project was based
- Ensuring the project report be sufficiently detailed, with a summary prepared for wider dissemination to staff, service users/clients, and others, as agreed by management
- Ensuring that reports of service evaluation clarify implications of the findings, and outline key recommendations

7.11 Dissemination and action plan

The dissemination of service evaluation project reports is a crucial step in the evaluation quality cycle. It allows not only awareness-raising but it encourages staff and clients who have engaged with the evaluation to reflect on the process, and on the results. It also enables stakeholders and staff to reflect on the implications for the service in question and for other rehabilitation services.

Dissemination opens up a process in an organisation, including within management, which fosters reflection, discussion and curiosity about the nature of the services provided. This process can inform the actions which follow within the rehabilitation service. Actions may include changes in service provision, procedures and practices. They may include asking different service evaluation questions, perhaps combining them with audit questions, to provide more in-depth understanding of the quality of particular services, or of all services combined. Actions may include changes to future evaluation project designs or implementation of these, changes to tools used and changes in the focus of future projects (e.g. to other service components or client groups).

Good practice includes:
- Ensuring dissemination of service evaluation project findings, suitable to the range of audiences (e.g. clients, donors, stakeholders, staff, colleagues in the field/other centres)
- Encouraging dialogue, reflection and curiosity amongst staff and stakeholders, on the findings, their meanings, and their implications
- Ensuring action plans follow from dissemination and discussion of service evaluations
- Ensuring there are appropriate management mechanisms to ensure dissemination and action-planning

7.12 Implementation of change and review

All monitoring and evaluation activities, as part of quality cycles, require some action to follow on

from the findings, to make necessary changes and improvements. As such, both monitoring and evaluation are inevitably tools in organisational change. The process of reviewing the impact of changes can be simultaneous with the process of implementation. The impact of both positive and negative changes needs to be reviewed and reflected upon to inform future service evaluations.

This process is essentially a management responsibility, though it should not be seen solely as management-driven. Ideally, actions agreed, in discussion with staff, can be followed through and changes implemented with collective effort and a commitment to professional and ethical practice – where every staff member acknowledges their obligation to contribute to the provision of high quality rehabilitation services to all torture survivors. Nevertheless, it is essential to have effective leadership in the change management process.

In summary, the process of change management is complex and service providers need to attend not just to collecting and reporting information, but to what is done with that information, and how change is facilitated in the organisation as a result of monitoring and evaluation findings.

Considerations in change management are summarised in Box 14.

Good practice includes:
- Ensuring effective mechanisms for implementing changes which have been identified and agreed, following the service evaluation project
- Ensuring all staff are aware of their roles and responsibilities, including professional and ethical responsibilities, in implementing changes agreed, and in contributing to the process of reviewing the impact of changes made.
- Ensuring effective leadership in managing change arising from service evaluations

Box 14 Considerations in change management

- **Visualising change together:** Consulting widely and developing a shared understanding within the organisation of what needs to change can support change processes as staff are more able to understand the reasons and necessity for change.
- **Communication:** Stimulating discussion, reflection and debate on feedback from monitoring and evaluation, and changes expected, with openness and honesty, is both necessary and healthy in an organisation. Good, mutually respectful communication across the organisation allows diverse viewpoints to be aired, broadening of staff awareness of alternative explanations for the findings from monitoring and service evaluations, and identification of alternative solutions.
- **Uncertainty:** All change involves uncertainty about what will change, how roles and practices will alter, and implications for staff and clients. This can raise anxiety in staff, manifested in conflict, tense communications, mutual blame and criticism, competition, passivity, helplessness and withdrawal. It is helpful always to attend to these processes, and to reflect on the anxiety that change engenders. When change feels relentless, for example when there are repeated changes, it is not unusual for staff to feel angry and to question the need. The ongoing process of monitoring and evaluation can be experienced as fuelling 'change fatigue', risking staff becoming disengaged, demoralised and overburdened. Allowing staff to express their concerns and anxieties about change, and acknowledging the impact of change, can enable

dialogue, improve mutual understanding, and may result in adjustment to the implementation plan.

- **Loss:** Change also involves loss. Some changes mean breaking from the past, from familiar practices. Certain practices may have to change, or certain services end or be re-structured. This can lead to a sense of loss for services sometimes cherished by staff, even if they are no longer viable. It can also lead to a loss of staff, if posts are changed or no longer necessary. Loss can be experienced in many ways, including in the expression of anger, denial, disengagement, resistance and disorientation. Openness to reflection on these processes, and on the meaning of changes and losses, is essential to managing the change, and to sustaining the changes made to improve services.

- **Ongoing management support:** Sustaining changes require management support, to be attentive to 'teething problems' and continued doubts, frustrations, anxieties, and to identify unanticipated problems which arise as a result of the changes. The transition to new practices, procedures and service structures require management to nurture new ideas and, sometimes, changes in organisational culture, encouraging staff to take risks, to try different ways, and to provide feedback on how well these new ways or practices are working

- **Motivation:** Change processes can leave management, staff and clients, feeling demotivated and demoralised. Management investment of energy and commitment to staff is essential, in inspiring, encouraging and giving positive feedback to them, as well as involving them meaningfully, not in a tokenistic way, in problem-solving together. All staff need be reminded that they are valued, that they each have responsibilities and a role to play, and that their contributions are important.

- **Time:** Sustaining changes also requires time, for changes to be established and for any improvements to be seen. Repeating audit projects and service evaluations too frequently and prematurely can be counterproductive because it leads to change fatigue and creates resistance to monitoring and evaluation. Also, significant changes may not be evident immediately.

- **Resources:** Lack of resources can also impede or destroy the best laid plans for change. Implementation requires a careful assessment of the resource implications, and effective leadership.

7.13 Indicators of an effective service evaluation system

As is the case with establishing a routine monitoring system, the establishment of an effective service evaluation system is also an important investment in organisation-building. An effective service evaluation system is safe, secure, ethical, meets the organisation's needs, and helps inform rehabilitative practice, service development and strategic planning.

More specifically, an effective service evaluation system is one which can:
- Evaluate the organisation's services and activities, against the organisation's goals and against established standards
- Meet the organisation's needs: help improve services, help inform rehabilitation practice; contribute to strategic planning of the organisation
- Conduct routine and ethical outcome monitoring across all services provided, using

appropriate tools and indicators

- Evaluate different and specific components (e.g. family services, legal support services) and aspects of rehabilitation services and activities, according to organisational priorities, against criteria for quality (e.g. appropriateness, impact, effectiveness), using appropriate and ethical methods
- Identify strengths, weaknesses, areas of good practice and gaps in services
- Ensure change is implemented as a result of feedback from clients and from service evaluations
- Disseminate information from service evaluations to staff, management, clients, stakeholders and donors, as well as to colleagues in the field, to promote learning and good practice

7.14 Summary

Conducting evaluation projects requires time, resources, knowledge and skills in research methods. While services, under pressure, may feel compelled to do some evaluation, it is essential that client care and safety are not compromised. Partial evaluations, starting to collect data without knowing the purpose or having the time to analyse it, are unwise.

Services would be advised to start small pilot projects, and refine services and methods in small ways, until resources, skills and time allow more and broader service evaluation projects. At minimum, services may consider seeking feedback from clients in various ways, though recognising that this is not a substitute for service evaluations. Ideally, service evaluations, and other ways of seeking feedback from clients, should focus on key standards of high quality rehabilitation services (Section 3).

Key steps in conducting overall service evaluations are summarised in Figure 7.

Step 1:
Agree on
- Standards and targets
- Focus of evaluation
- Aims of the evaluation

Step 2:
Identify
- Competency: relevant knowledge and skills
- Resources and organisational willingness

Step 3:
Define
- Approaches to seeking feedback on services
- Service evaluation questions
- Research project and proposal

Step 4:
Ethics
- Seek ethical approval
- Ensure ethical and professional practice throughout

Step 5:
Reporting
- Will depend on requirements of organisation
- Should include a written report
- Should outline key recommendations

Step 6:
Dissemination
- Should be suitable to audiences
- Should encourage dialogue, reflection and change

Step 7:
Implementation
- Ensure effective mechanism for implementation of change
- Ensure all staff understand responsibility for improvement and change
- Ensure effective leadership arises from service evaluation

Figure 7. Key steps in conducting overall service evaluations

8. Clinical outcome evaluation

Clinical outcomes are the changes intended from intervention with clients, families, or whole groups or communities. They are a component of service evaluation, as stated in Section 7, much of which applies here. In particular, 7.3 on the cycle of evaluation, 7.4 on competency in conducting evaluations, 7.7 on designing evaluation, and 7.8 on seeking ethical approval apply completely to clinical outcomes so are not repeated here, except in relation to specific considerations.

Evaluating outcomes, as with other evaluation, requires clarity on the aims of intervention, on the diverse outcomes of relevance to the organisation and its services, and skills and competencies in using rigorous methods which ensure ethical practice, accurate data, and findings which represent the situation as truly as possible. Human complexity makes these tasks difficult; nevertheless, without them we risk wasting resources that could be better used for client benefit, squandering staff skills and effort, and even making our clients' lives worse despite our good intentions.

8.1 Definition of clinical outcome evaluation

As noted in Section 7, evaluation is the systematic measurement of events or processes, and their interpretation, using specified criteria related to underlying theory or aims. In the context of services for torture survivors, it might measure what the service provides according to quality standards (service evaluation: see Section 7), or focus specifically on clinical outcomes. Clinical outcome evaluation measures changes in health of clients that result from the care provided. Clinical outcome evaluation can be a constant review of changes against standards to continuously improve service practices (routine clinical outcome monitoring); it can be a component of service evaluation projects, or it can be stand-alone research. It is important, however, to recognise that a service evaluation falls far short of the requirements of a scientific trial, in which therapeutic intervention and its delivery is designed to answer a specific question as definitively as possible: a daunting task and one outside the remit of this handbook.

It is unrealistic for rehabilitation services to be expected to attempt such scientific trials, or to invest precious resources for monitoring and evaluation in conducting them, especially where routine monitoring and service evaluations have not been addressed. It is also unethical for such scientific trials to be conducted by those lacking in appropriate competencies. It is ethically highly questionable to permit the restrictive requirements of a scientific trial to dictate service provision and access to specific services or interventions to some torture survivors, whilst denying them to others equally in need. However, rehabilitation services should be open to approaches by suitably qualified researchers to explore the possibility of mutually beneficial research activity, taking all client and organisational needs, and ethical considerations, into account.

All evaluation methods need to be, as far as possible, simple, realistic, meaningful, valid, and ethical. While this seems a short list, each of these requirements generates many further considerations which are explored below, and with some solutions offered.

8.2 Types of clinical outcome evaluation

The choice of output indicators is related to the aims and objectives of the service, as defined by the stakeholders including funders, staff, and service users, and those are the people who put values on the outputs. A service, for instance, may aim to increase its overall number of users per year, or to increase the number of users who attend more than once, or to increase attendance by

a particular group; each of these requires specific data to be collected as efficiently and completely as possible.

As noted in Section 7, outcome evaluation is concerned with questions about whether and how the service 'works'; the benefits and disadvantages to those who use it, and whether there are systematic factors underlying who benefits and who does not; and how the services are experienced by clients in relation to their expectations and hopes, how satisfied they are and what contributes to their satisfaction. All these are essential to inform initiatives to improve the effectiveness (and often cost-effectiveness) of the service.

In their review of the history of evaluation of torture rehabilitation programmes, Jaranson and Quiroga (2011)[5] date them from 1975 in Chile and 1979 in Argentina. Programmes drew on wide community and political resources, as well as the established professions working in psychological and psychiatric treatment. Survivors of the Holocaust and their children had been treated in individual psychotherapies, some of which were published as case histories, but the first torture rehabilitation programmes in Europe and North America began in the 1980s, largely based around medical personnel in local branches of Amnesty International. Jaranson and Quiroga estimated that there were at least 235 centres worldwide at the time of writing their review in 2011. Programmes predominantly treated psychological problems, usually formulated in orthodox psychiatric terminology, of refugees from various countries. Jaranson and Quiroga noted few outcome studies among the accounts of treatment, and indeed little agreement on key outcomes; they also recognised the need for adequately trained academic personnel to address questions of treatment efficacy (does it work in a controlled trial?) and effectiveness (does it work in clinical practice?). Such needs are rarely met within existing programme resources.

Questions typically addressed by clinical outcome evaluation
One of the most widespread purposes of evaluation is to ascertain the gains made by clients using a service, and/or lack of change or even worsening, and to understand their experience of using the service. Here for ease of reading the term 'client' is used, but the client may be a parent and child/ren, a family, a group or (more rarely) a whole community.
- Did clients show benefit in the target of intervention?
- Did clients of that intervention show other benefits?
- Did improvement reach a specified goal (falling below a diagnostic criterion, for instance) or show equivalence to established equivalent services
- Did some clients worsen?
- Why did clients drop out of treatment before completion?
- What did clients experience as the benefits of treatment?
- Were there aspects of treatment that they found unhelpful?
- Were the clients who improved from an identifiable subgroup of clients (e.g. more educated, therapy in own language, already had asylum status, stable living conditions, etc.)?
- Were the clients who worsened or dropped out from an identifiable subgroup?
- Was there a relationship between improvement in one problem area and improvement in another (for instance, did those who showed an improvement in depression also reliably report improved sleep quality)?

The two main methodologies for evaluation are quantitative and qualitative, and they can be used alongside one another effectively (often referred to as 'mixed methods approach'). Each

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5 Jaranson JM, Quiroga J. Evaluating the services of torture rehabilitation programmes. Torture 2011; 21(2):98-140.

methodology has a range of methods suited to specific types of evaluation questions. What is important is that the evaluation be related to the mission, goals, objectives and clientele of the service, and as far as possible integrated into its work.

8.3 Formulating evaluation questions

Beyond data description, there is scope for asking many questions of the data, and this is both a strength and a problem. It is tempting to fish for answers before refining the questions, and then to construct explanations for what has been found, but this is unscientific and often misleading. Constructing questions for outcome evaluation, unless the protocol already specifies those questions, is an iterative process between those who provide the service, those who are familiar with the data, and collaborators who are experienced researchers. So many diverse factors affect the lives and wellbeing of refugees that it can be bewildering to know what to take into account and what questions can be answered.

One of the most important questions is: were clients better when they left the service than when they arrived? To answer that requires considering the following questions:

- Who is a client: anyone who makes contact; anyone who joins a therapeutic programme of any sort; anyone who completes the planned care package?
- Better in what way, given the data collected: quality of life; psychological symptoms; asylum status?
- Better according to whose criteria?
- How much better? This is a complex question with several possible solutions, all of which have shortcomings as well as strengths, and this is why it is important that the data be analysed with reference to the overall aims of the project and realistic understanding of what can be achieved.

Consulting on purpose of evaluation

The purpose of evaluation needs to be established through broad consultation with rehabilitation service staff, current, prospective and ex-clients, referrers, and other interested parties. Mission statements or explicit aims of services may provide a starting point, but may also require revision in this process. It is most common for evaluation instruments to be devised by researchers and service staff without reference to the client group until the piloting stage, but that is too late for clients' hopes and expectations of the service, and clients' priorities, to be elicited.

Focus groups and/or interviews or written narratives, using questions such as (to a prospective client) "If this service met your needs, what would be different when you left it?", and (to a clinician) "If you felt you had really failed with a client, how would that be evident?" Data from these exercises is then analysed for themes of outcome, desired, to be avoided, and a sense of what is valued most highly, particularly if this differs across groups. Services may be wary of doing such an exercise, fearing that it will set unrealistic expectations against which their outcomes will look very poor, and will require reassurance that the data will in fact help to ground outcome evaluation in realistic expectations.

It is only by routine measurement of all service users, or of a truly random sample (hard to achieve in a clinical service) that a service can start to answer important questions: what gains are clients making? What size are those gains, at best, on average and at least? Do some clients get worse? It can even address questions such as: do longer treatments bring about greater changes than shorter, or do gains tend to level off? Services may hope that these data will help them predict 'which clients will do best', but retrospective association of baseline characteristics with outcomes will not tell them that. The data are essential though for reviewing services and practice (such as number of sessions offered, or whether long waits to receive a service result in poorer outcomes),

and for assessing the effects of change as a result of the review.

8.4 Deciding on clinical outcomes to evaluate

Following discussion and consensus around the purposes of evaluation, the questions need to be refined to arrive at the types of outcome, the domains of outcome, and the way in which the data will be used.

Types of clinical outcome

Outcomes may be specified as achievement or not of specific goals, or the amount of improvement in a problem area or towards a specific goal of health or wellbeing.

Specific goals

This is (or appears to be) the simplest level of question to answer. The service may have provided help towards a specific goal: a medico-legal assessment for asylum determination procedures; support and advice for finding work or building livelihoods; being able to speak and understand the language in the host country sufficiently for day to day needs. Even these are hard to dichotomise (having only two possible values) as achieved or not: for instance, the client may have work but not at a job he or she wishes to do and is able to do. This means that outcome categories may need to specify levels of achievement.

Change in health or wellbeing

This is a more complex question. Evaluating change in this area will generally rely on scores of questionnaires described below, but these do not necessarily extend to individual issues in which improvement is highly valued by client and service provider, such as the specific goals above. It is common in academic studies to seek to establish whether an observed difference is due to chance or not. Such studies may rely on the statistical significance of change, which usually compares means in terms of standard deviation, so that the bigger the variance (and therefore the standard deviation), the bigger the difference between the means of baseline and final values, for a given population. The problem is that a difference can be statistically significant and yet fairly trivial from the point of view of the client and those providing help. For instance, the difference achieved by one particular treatment for torture survivors with post-traumatic stress disorder was statistically significant, but in fact the average symptom score reduced from the 'very severe' range to the top of the 'severe' range (Patel et al., in press[6]); the client and others might have hoped to reduce symptoms to a mild level, requiring a far larger change. Methods for estimating clinically significant change from statistical data are beyond the scope of these guidelines (Hsu, 1999[7]; Jacobson et al., 1999[8]; Kendall et al. 1999[9]).

Interpreting change is also an issue which requires consideration and planning. In some circumstances, there may be data from populations which are not torture survivors with which endpoints of treatment can be compared, although it is important to ensure that the populations

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6 Patel N, Kellezi B, Williams ACdeC. Psychological, social and welfare interventions for psychological health and well-being of torture survivors. Cochrane Library in press 2014.

7 Hsu LM. Caveats concerning comparisons of change rates obtained with five methods of identifying significant client changes: comment on Speer and Greenbaum (1995), J Consult Clin Psychol 1999; 67:594-598.

8 Jacobson NS, Roberts LJ, Berns SB, McGlinchey JB. Methods for defining and determining the clinical significance of treatment effects: description, application, and alternatives. J Consult Clin Psychol 1999; 67:300-307.

9 Kendall PC, Marrs-Garcia A, Nath SR, Sheldrick RC. Normative comparisons for the evaluation of clinical significance, J Consult Clin Psychol 1999; 47:285-299.

10 Jensen MP, Karoly P. Self-report scales and procedures for assessing pain in adults. In DC Turk, R Melzack (eds.), Handbook of Pain Assessment 2nd edn. New York: Guilford Press, 2001, pp.15–34.

are otherwise comparable, in basic characteristics such as age, for example. In others, a score close to zero is effectively the 'normal' score, meaning few or no problems in the relevant area, and change can be judged in relation to zero as the target. Change may be judged by percentage, although this is in most cases hard to map on to quantified experience such as depression. For sleep problems, halving the number of nightmares, or night-time awakenings, may be a meaningful target, and for acute pain it is common to set a 30% or 50% reduction in pain rating as the target (Jensen and Karoly, 2001[10]). It is also possible to use published data from similar work or from meta-analyses to benchmark outcomes, again, ensuring that the populations being compared are sufficiently similar for this to be valid.

Domains of outcome

Domains can be defined as broad categories of health or wellbeing within which more specific clinical outcomes may be identified. For instance, within the domain of 'health' is 'physical health' and 'psychological health' (and also, possibly, 'family health', etc.). Within psychological health, distinctions may be made between particular problem areas, diagnoses, or symptom groups, or the category may be treated as a single unitary one. This is a decision about level of detail feasible, desirable, and appropriate to the purpose of evaluation.

The themes from discussion of the purpose of evaluation are likely to identify, or to help to identify, a range of outcomes. Some will be defined as specific goals, categorical outcomes, such as 'in stable accommodation', 'employed', 'discharged from psychiatric care', but these are often subject to influences beyond the health and efforts of the client, and may not even be clear categories; for instance, some instruments count care of school age children or full time education as work, and others define work only as paid employment. Others will be improvement in a problem area, such as 'mood', 'trauma symptoms', 'quality of life', 'family relationships', which although they are related also have a unique content. These are all continuous concepts, in which improvement is represented by a change along a continuum.

Within each domain, a search will usually identify a choice of measurement instruments: the many considerations in choosing the best one given the aims and methods of the service are explored below. The long list which results from this process will usually need to be pruned to make a set which is manageable for clients and for data entry and analysis. There is always a compromise between inclusiveness and brevity, and on the level of description, from very specific to generic. Sometimes the best option is to adapt or create questions for particular purposes, but this needs some understanding of the process of assessment (Boynton, 2004[11]; Boynton and Greenhalgh, 2004[12]), and without data on how the question performs (for instance, is it even measuring what it claims to measure?), it may be hard to interpret and use the data it produces.

How will the data be used?

Once outcome is under examination, there are many ways of further investigating it. Are there characteristics of clients (such as sex), of therapists (such as years of experience), of intervention, of service delivery (such as duration or language), or other variables with which outcome varies? Asking these questions requires a reasonable number of clients in the database, and fairly complete data, or results are likely to be misleading. It is also crucial to recognise that extraneous factors can be very important in bringing about improvement or worsening (Jaranson and

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11 Boynton PM. Administering, analysing, and reporting your questionnaire. Brit Med J 2004;328:1372-1375.

12 Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. Brit Med J 2004;328:1312-1315.

Quiroga, 20115), events such as good or bad news of family or friends; obtaining leave to remain; a chance of accommodation. The general assumption in research on stable populations is that approximately equal numbers of positive and negative events will happen across the population, so that they do not need to be taken into account, but in refugee populations this may not be a valid assumption and there may need to be reference to clinical records to investigate a random sample, or to explore what the most extreme values represent.

All these examples demonstrate how important it is to consider these questions before analysing data, even if after analysis they are reconsidered. Other questions can be asked of the data, but are beyond the remit of this chapter and require expert assistance from experienced researchers.

Key steps

1. Operationalise the clinical outcomes with reference to the purposes of intervention and methods used by the project
2. Identify the domains within which these outcomes fall (physical health, psychological health, quality of life, social relationships, legal status, educational progress, etc.)
3. Establish the level of generality or detail at which each domain is to be assessed.
4. Where domains are to be assessed in detail, identify specific goals or categories and/or continuous qualities to be measured.
5. Specify the question to be asked: is it about degree of improvement, or matching improvement against some external criterion, or demonstrating a trajectory of change, etc.
6. Ensure that there are assessments in place which will identify worsening as well as improvement.

Key challenges

In many areas of health research, there are clear priorities for treatment which also constitute the outcomes, usually best health (such as freedom from infection, or a mended fracture) with fewest adverse effects from treatment and minimal impact of the temporary illness. Ideally, clinicians and clients agree on those priorities and outcomes, and this makes it easier to compare one treatment with another and to agree on which is best for the particular client. In the area of mental health, indicators of good and poor health are harder to define, more subject to cultural difference, and difficult to measure, problems which often generate diverse treatments and diverse outcomes, and this makes it almost impossible to compare treatments. However, treatment service claims of efficacy, acceptability, and lack of adverse effects need to be substantiated, and preferably in terms shared by cognate areas so that clinicians, clients, funders and others can direct efforts and resources to what is likely to produce the best results.

8.5 Choosing evaluation tools

Matching available instruments to domains of interest and importance is not an easy task. Similar services might offer precedents, but this should never substitute for the exploration described above. Assessment instruments are given titles which appear to offer efficient measurement of the concept in question, but concepts are rarely clearly defined or distinct from others in the same or related domains.

Few concepts in psychology map adequately on to physiological and brain processing correlates and related behaviours in animal or human research; fear and avoidance are the best example of ones which meet these requirements. Others may be conceptually coherent but open to reformulation

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13 Michell J. Quantitative science and the definition of measurement in psychology. Brit J Psychol 1997; 88:355-383.

using related concepts. Nor are these abstract concepts necessarily linear in organisation such that degrees of matching the concept can be simply arranged from most negative to most positive; there may be many different states with no stable order between these extremes (Michell, 1997[13]), a point conveniently overlooked in constructing measurement instruments.

In summary, when selecting evaluation tools it is important not simply to be tempted to use measures that claim to assess specific concepts, such as 'coping', but to examine carefully what concepts the measure may tap into, and whether and how these are relevant to the client population, given their experiences and cultural background.

Cultural appropriateness
Related to this but in effect an overarching problem is that of cultural appropriateness. Norms of behaviour, of expression, and concepts by which subjective experience is organised differ across and even within cultures. There are guidelines for investigating the suitability of a translated instrument in a culture different from that in which it was developed. These procedures are beyond the resources of most services, although services may provide the means by which academic partners can address them as research projects. This is explored in greater detail below, in 'Adapting an existing measure to another cultural and language group'.

Evaluation instruments are also used to diagnose and to select for treatment. This requires using threshold values derived from (ideally) a large and representative population. However, that population is usually stable and subject to very different traumatic events from torture survivors, in very different contexts, and far fewer. For this reason and for statistical reasons which are not detailed here, the threshold values are unlikely to apply, so should not be used as the sole basis for selection for treatment but supplemented or replaced by clinical decisions.

8.6 Selecting the most suitable clinical outcome evaluation tools

Fitzpatrick et al. (1998)[14] listed the criteria for selection of any assessment tool as: fitness for purpose, reliability, validity, sensitivity to change, precision in making distinctions, interpretability, acceptability, and feasibility. However, information available on these criteria about the tools within a single domain varies so that comparison can be difficult. It is difficult to balance quality of measurement (further explained below), usefulness of content, availability of the instrument (some charge for use), and availability in multiple languages or ease of translation against one another. As Jaranson and Quiroga (2011) comment in a helpful overview of evaluation of torture survivor services, there are no comparisons of candidate evaluation instruments in this field, so information is drawn from diverse sources to make the choice. A review of measures used in this field for trauma and health, by Hollifield et al. (2002)[15] is less up to date but demonstrates rigorous methods of selecting measures according to their qualities.

A simple internet search will produce older instruments, whose advantage is that there is information available on their quality, with a track record and credibility which helps interpretation and use in the wider field. But older instruments were often developed with weak theoretical foundations and rarely with user involvement, and not with torture survivor populations. Newer instruments can be harder to find but may have been developed in a more authentic way. Both old and new instruments may be copyrighted and require permission, a licence (possibly requiring

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14 Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials, Health Technol Assess 1998;2:14.

15 Hollifield M, Warner TD, Lian N, Krakow B, Jenkins JH, Kesler J, Stevenson J, Westermeyer J. Measuring trauma and health status in refugees: a critical review. J Amer Med Assoc 2002; 288(5):611-621.

evidence of qualification or training in test administration), and/or payment to use; others are freely available.

Psychology, the discipline in which most of the relevant instruments have been developed, focuses on subjective experience of various sorts, with some sophistication, but usually neglects interpersonal and broader social and cultural factors which influence subjective experience, behaviour, options in life and resources. There is a socioeconomic class gradient with most psychological problems, and certainly in options and resources. There are often gender and age differences which are not well represented when interpreting measures, except some quality of life instruments. Torture survivors are often multiply disadvantaged: extremely poor, subject to individual and institutional discrimination, and often isolated from their family, community, ethnic, religious, and language groups. It can be difficult to quantify many of these variables and to use them in interpreting outcomes, and in some situations, those conditions themselves – such as integration into a community with common culture – are themselves important outcomes.

Translation of concepts and content
Ideally, an instrument for use across various different cultures and language groups would be developed simultaneously in those culture and language groups, each informing the other throughout development. This avoids the ethnocentrism in the much more common case of an English-language measure being adapted for use in other cultural and language groups (Tanzer and Sim, 1999)[16]. Careful methodology can minimise this tendency, but it is expensive in time and resources. The commonest strategy is forward-translating an instrument from English to the target language, without consideration of conceptual equivalence, cultural appropriateness, or testing the translation. This is liable to produce results with unknown biases, compromising reliability, and potentially obscuring the meaning of data produced using it, problems serious enough to threaten the ethical status of the practice (see Nickerson et al., 2010[17]; Patel 1999[18], 2003[19]; Patel et al., 2000[20]).

Exploring concepts in mental health
Broad-scope (focus groups, community meetings, surveys) and in-depth (interviews, observational studies) qualitative methods combine to develop understanding of relevant constructs and their interrelationships (Napoles-Springer and Stewart, 2006[21], Johnson, 2006[22]). Many academics

16 Tanzer NK, Sim CQE. Adapting instruments for use in multiple languages and cultures: a review of the ITC guidelines for test adaptations. Eur J Psychol Assess 1999;15:258-269.

17 Nickerson A, Bryant RA Silove D, Steel Z. A critical review of psychological treatments of posttraumatic stress disorder in refugees. Clin Psychol Rev 2010; 39 (3):399–417.

18 Patel N. Getting the Evidence: Ethical Guidelines for mental health research involving 'race', ethnicity and culture. London: Transcultural Psychiatry Society, UK & MIND, 1999.

19 Patel N. Clinical psychology: Reinforcing inequalities or facilitating empowerment? Intern J Human Rights 2003; 7:16-39.

20 Patel N, Bennett E, Dennis M, Dosanjh N, Miller A, Mahtani A, Nadirshaw Z. (eds.) Clinical Psychology, Race & Culture: A Training Manual. Blackwell: Chichester, 2000.

21 Napoles-Springer AM, Stewart AL. Overview of qualitative methods in research with diverse populations. Med Care 2006;44:S5-S9.

22 Johnson TP. Methods and frameworks for cross-cultural measurement. Med Care 2006;44:S17-S20.

23 Summerfield D. The invention of post-traumatic stress disorder and the social usefulness of a psychiatric category. Brit Med J 2001; 322: 95-98.

24 Karasz A. Cultural differences in conceptual models of depression. Soc Sci Medicine 2005; 60:1625-1635.

25 Sousa VD, Rojjanasrirat W. Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. J Eval Clin Practice 2011; 17:268-274.

and clinicians challenge the extrapolation of psychiatric diagnoses across cultures and contexts (Summerfield, 2001[23]; Nickerson et al., 201017), for instance, and exploration of common psychological experiences produces novel findings on cultural differences in formulation of problems and in explanatory frameworks (e.g. Karasz 2005[24]).

Adapting an existing measure to another cultural and language group

The guidelines which follow draw very extensively on the user-friendly guide by Sousa and Rojjanasrirat (2011)[25]. They apply only when explorations of the concept in the target population have shown sufficient equivalence, and when the format and presentation of the instrument is appropriate for the population.

1. Forward translation of instructions, items, response options, and scoring methods from source to target language. This should be done independently by two qualified translators or translation teams whose first language is the target language, and who between them have expertise in the relevant area of health care and in current idiom and colloquial terms of relevance.

2. The two versions are compared by an independent small team of bilingual people who resolve differences or ambiguities in discussion with the translators and a member of the research team.

3. Back translation of the agreed version into the source language, under the same conditions as 1.

4. The two versions are compared with one another and with the original, and differences resolved in discussion with all four translators, a team with expertise in healthcare and in methodology. Ideally the originator of the instrument is also involved. Differences that cannot be resolved require repetition of steps 1-3. When complete, this process ensures the conceptual and semantic equivalence of the translated version to the original instrument.

5. Pilot testing of the translation by 10-40 members of the target population, whose language is the target language, who rate as clear or unclear each component of instructions, items, etc. 80% agreement between raters is the minimum; this may necessitate repeating steps 1-4 for particular components. An expert panel with expertise in the relevant area of healthcare and whose first language is the target language also rates each component for content validity, using the scale not relevant / unable to assess relevance / relevant but needs minor alteration / relevant and clear. Items rated in the first two categories require revision by repeating earlier steps. At this point, methodological expertise is required to calculate validity indices.

6. Preliminary testing on bilingual people from the population of concern is ideal but a difficult condition to meet, so meeting the bilingualism criterion is valued above involving relevant participants. A minimum of 5 times the number of items is required: for a 20-item instrument, a minimum of 100 participants is needed. These participants respond to the instrument in the translated and in the original versions, varying the order of items in the translation to disrupt comparison. Major discrepancies require a return to the previous step for discussion.

7. The final step is testing of psychometric properties (see the section below on Validity and Reliability), which vary according to the purpose of the instrument: while all require calculation of internal consistency (reliability), and statements about validation attempts, a diagnostic measure is also described in terms of sensitivity and specificity; an observation tool has inter-rater reliability. At this point, participant numbers need to be at least 10 times the number of items, and the enterprise needs trained academic support, and considerable resources to have adequate sample sizes for the analyses.

When literacy levels are very low, one option is to use trained interpreters to read instruments to participants in their own language, but instruments should be carefully chosen to be feasible in

this format. For instance, reading several alternative statements which the respondent has to keep in mind to choose the most suitable is impractical, whereas a 'yes', 'no', or degree of frequency or agreement option to a short statement is undemanding. Alternatively, qualitative methods should be considered, as described later in this section.

Interpreters who help in assessment in this way need to be trained to do so in as standardised a way as possible. It inevitably changes the way in which assessment is experienced to be asked the questions by another, particularly where they address sensitive and personal areas of life, rather than to respond privately to a self-report format on paper or computer. It is tempting to offer answers to a client who is hesitating or struggling, or to skip questions thought not to be relevant, but this risks invalidating the tool. It is also demanding of resources, leading to pressures to minimise or even eliminate assessment of clients who do not speak the language of the assessment tool.

Accountability

We are a long way from evaluation as routine practice in mainstream State and NGO services. The experience of service users in designing, conducting and reflecting on analyses in evaluation studies is still neglected, and there is often little attempt to explain, beyond confidentiality required by data protection, what use is made of the data, and whether there are benefits for the individual completing the evaluation. Service monitoring and improvement is generally accepted as a good reason to evaluate, engaging clients' altruism towards those torture survivors who may also use the services in future. But it may also be that important decisions, such as whether a client is in need of continued rehabilitation care or treatment, which draw narrowly on scores on measures or on the presence or absence of diagnoses, are then used to make even more critical judgements, such as right to asylum. There are few guidelines to good practice in this area.

There are genuine barriers to evaluation, and these are often cited as reasons not to attempt it. Being met by a pile of questionnaires to fill at a first appointment can seem insensitive, bureaucratic and even brutal, particularly for the client in distress or crisis, and this may seriously impede engagement and cause further distress to the client. Even a well-chosen set of instruments may seem inappropriate for the client with severe and complex psychological problems. Doubts about cultural appropriateness of the constructs to be measured, or the questions on the instruments (which can be experienced as intrusive and offensive), are serious considerations, and where the instruments are interpreted in real time, it is clear that unsystematic error variance is introduced by the approximations in language.

Evaluation is in part an exercise in accountability: to fail to attempt evaluation or analyse the data (very common in the days of pen-and-paper data collection) is ethically problematic. A service that claims, even if implicitly, that it offers skilled practice in 'evidence-based treatment methods' should at a minimum benchmark outcomes against published outcomes. Services should also be honest about the lack of evidence or of demonstrated efficacy, and open about the basis for deciding on therapeutic methods and practices.

Validity and reliability

An instrument whose content has not been scrutinized or tested for cultural appropriateness and for its properties in the target population may produce entirely unreliable results because of the unexpected and/or inconsistent ways in which content or response options, or even the overall instructions, are interpreted by respondents.

Weakness or lack of established reliability and validity raise concerns that the instruments are not measuring what they purport to measure, and that their design is not fit for purpose. This can be seriously misleading, and therefore lead to poor decisions: since this is avoidable, it is an ethical issue to ensure as far as possible that instruments used have at least adequate reliability and validity, and that they are interpreted with understanding of these properties.

Inclusiveness

Scales are constructed by developing and testing items representing all the facets of the chosen concept, and the full set is reduced as far as possible to the smallest number best representing the concept with coherence; that is, without being subject to substantial influence of other related concepts. However, that pruning may remove items of clinical interest and importance, and which commonly co-occur with the concept of interest. For instance, anxiety and depression instruments have been designed to distinguish the two by removing items which occur in both, but it is common for people to experience symptoms of anxiety and depression together, so each instrument is somewhat artificial in its boundaries. Note that a single measure of distress, for instance, could contain items relating both to anxiety and depression.

Reliability

Reliability of a scale describes the extent to which differences in scores represent differences in the concept of interest, rather than reflecting unattributable error. Thus, an instrument used on two different occasions and/or by different evaluators of a stable condition should produce the same answer. It has been likened to measurement with a ruler rather than with a piece of elastic (Powell, 1996)[26].

Reliability is maximised by ensuring that items in a scale correlate well with one another and with the total (internal reliability or consistency), and by minimising sources of unsystematic error, such as ambiguity which elicits different answers according to how it is understood. Inter-rater reliability and test-retest reliability are, respectively, consistency between raters (diagnosticians, for instance), and consistency across time (although often shorter than the interval between pre- and post-treatment measurement). A reliability coefficient is often considered 'good' if it is at least 0.8, but even this implies that a third of the variance is random. Any reliability coefficient is a property of the instrument in the context of the population/s it was tested on, so the more representative these samples are of the population of concern, the more confidently can the instrument be used.

Validity

Validity is an aim or work in progress rather than a fixed property, and describes the extent to which the instrument actually measures the concept of interest, rather than a related but not identical one, or by systematic or random error. It is dependent on reliability, but this is not sufficient to ensure validity. To return to the example of the ruler or elastic for measurement of length, both may have standard units of length marked on them so that used the same way on different occasions, they produce the same answer. To be valid, however, the ruler would need to be calibrated against a universal standard of length. Validity is described in several different ways (see McDowell, 2006[27]), defined by the possibilities for comparison.

26 Powell GE. The selection and development of measures. In G Parry, FN Watts (eds.), Behavioural and mental health research: a handbook of skills and methods. Hove UK, Erlbaum, 1996, pp 29-57.

27 McDowell I. Measuring health: a guide to rating scales and questionnaires. Oxford, Oxford University Press, 2006.

Construct validity indicates how well the instrument under test measures the concept (construct) of interest. That construct is almost always represented either by likeness to similar instruments or expert judgments as in diagnosis (concurrent validity), or by difference from instruments measuring different constructs (discriminant validity), but these are only rather general indicators. In psychosocial healthcare, there are rarely agreed definitions of the concepts of interest, and difference in definition inevitably generate differences in measurement tools. The method of asking those who complete the instrument (assuming it is self-report) to reflect on it, to describe how they arrived at their answers, and what it means to them, is under-used but can give considerable insight into content and coverage.

Criterion validity is an index of the extent to which the new instrument measures what an already established instrument measures. In medicine, measuring the pulse with a finger at the wrist is a valid measure of heart rate, more accurately measured by a stethoscope over the heart. It is clear how the two are related, and listening directly to the heart is the 'gold standard'. In subjective measurement there are no gold standards. An instrument measuring depression can be matched against experienced diagnoses or an existing widely used depression instrument, but neither can claim to be a gold standard, although treated as such. Of course, a weak relationship of a new instrument either to a long-established one or to expert diagnosis would call its validity into question. (Scientific Advisory Committee of the Medical Outcomes Trust, 2002[28]; Terwee et al., 2003[29]).

Predictive validity is related to criterion validity. It is often used to describe statistical prediction, such as of meeting diagnostic criteria, but is more impressive when it actually predicts real events, such as achieving a previously avoided activity, with reasonable accuracy.

Face validity is the appearance of authenticity of an instrument in relation to the construct of interest, most importantly to those who respond to it, but also to those who administer it. For instance, a measure of educational level which assessed only numeracy would have low face validity, particularly for those respondents whose numeracy skills were substantially poorer than their literacy and other attainments.

Sensitivity to change: An instrument which measures what it claims to measure and with relatively little error – that is reliable and valid within the bounds of testing conditions – should be sensitive to change, so long as the change falls within the range of the instrument. An instrument for measuring social function in the community, full of items concerning work, leisure pursuits, and family activity, may not adequately identify the extreme isolation of some refugees with none of these, nor the resources and opportunities for social contact with those from the same culture or language.

Implications of reliability, validity, and sensitivity to change
All these concerns have important clinical implications. If an instrument has relatively low reliability, identifying and interpreting differences in scores between groups or before and after treatment will be problematic, as the extent of (unaccounted for) error of measurement puts a large margin of uncertainty around that difference or change, or around a target score. If the instrument has low validity, it will misclassify people and mislead about their needs. Many

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28 Scientific Advisory Committee of the Medical Outcomes Trust. Assessing health status and quality-of-life instruments: attributes and review criteria, Qual Life Res 2002; 11: 193-205.

29 Terwee CB, Dekker FWS, Wiersinga WM, Prummel MF, Bossuyt PMM. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation, Qual Life Res 2003; 12:349-362.

treatment studies rely on statistical significance of change in scores on a particular instrument to support claims of efficacy, and that is undermined by shortcomings in reliability and validity. This is discussed further below under methods of analysis and reporting data.

Key questions to ask about candidate measurement tools

1. Does it cover the range of difficulties experienced by clients, or was it developed and standardised on a very different population?
2. Is it reliable, as a coherent concept, and for repeated assessments?
3. What validation attempts have been undertaken and do they assure me that the tool will measure what it says it measures in the relevant population?
4. Will it be able to show change of the size expected in this client group (sensitivity to change)?
5. If it is a screening tool used to make decisions, for instance about treatment eligibility, what is the balance of false positives and false negatives, usually referred to as sensitivity and specificity?
6. Is it available in the language/s used by clients? If not, are the resources to develop a translated version available? If not, how can best can standardised assessments be conducted using interpreters?

8.7 Quantitative approach

One of the commonest approaches to clinical outcome evaluation is quantitative. Whilst there are strengths of this approach, there are also various issues which need consideration when adopting this approach with torture survivors. Some of these are outlined below.

Scale content

What matters about quantifying psychological experience is how well this represents the problems and the priorities of the people who are completing the instruments. In some cases, countable events are a reason for seeking treatment and the target of treatment. Nightmares, for instance, are often profoundly distressing, disrupting sleep and thereby daytime functioning, with effects on family members or hostel roommates. Nightmares which wake the sleeper can be counted and the aim of treatment is to reduce them to as near zero as possible. Activities to be increased, such as attendance at a class, or initiating a conversation, are also countable although may be more subject to external influences. This method of assessing change can be described as transparent, in that there is no interpretation needed to understand the direction and extent of change.

But as described above, many of the reasons for seeking help or offering treatment are best described and measured using compound concepts such as depression, or quality of life, and the instruments devised to measure them inevitably match some people's difficulties better than others, varying with unidentified factors which may be more or less relevant. Scores on continuous scales require interpretation and although there are guidelines on this, experts may still disagree on the meaning of a score or difference in scores. It is common for 'clinical significance' of change to be calculated by reference to population norms and statistical properties of responses across large numbers of people (Jacobson et al. 19998), but with no reference to what the target population, say torture survivors, regard as a minimum worthwhile amount of change.

Response format

Further problems arise from the way in which a questionnaire is designed. Items may represent symptoms (as in depression, post-traumatic stress, etc.) or statements (of belief or emotion, for instance) or other aspects of the experience in question. Questions about symptoms may ask about them in terms of severity, frequency, duration, impact such interference with other activities, or

a mixture of those. There are advantages and disadvantages to each, and what matters is whether it makes sense in terms of the overall concept (for instance, it would not be sensible to ask about an emotional experience, such as anxiety, only in terms of how often the client felt anxious) and in terms of what is possible for the client to answer (questions about 'work', for instance, need to specify whether they mean only regular employment or whether they also include taking care of others, casual and unpaid work, etc.).

It is common to ask about frequency of an experience, such as having a flashback, using a metric of how often it is experienced, offering ranked options such as in the example below from the Post-Traumatic Disorder Scale (PDS)[30], where the experiences include reliving the traumatic event, and having bad dreams or nightmares.

Table 8.1 Frequency rating from Post-Traumatic Disorder Scale

Frequency	score
not at all or only one time	0
once a week or less/once in a while	1
2 to 4 times a week/half the time	2
5 or more times a week/ almost always	3

It is not uncommon for no actual frequencies to be specified, but the ranking to be presented in terms such as never 0, very rarely 1, sometimes 2, often 3, almost all the time 4. The numbers are available for scoring, but they also imply that the items are in some way evenly spaced in terms of frequency. One respondent may interpret 'sometimes' as 'anything less than daily', while another reads it as meaning 'less than once a fortnight'. It is common for the midpoint to be taken as some sort of norm, so that respondents answer partly by deciding whether they experience the problem more or less often than others around them (Schwarz 1999[31]): in this case, it depends on their reference group and the accuracy of their knowledge of others' experiences, both of which vary widely. Yet absolute counts are also difficult to answer: for frequent events (which flashbacks might be), respondents usually estimate by multiplying up from the number they remember in a short time span, perhaps the day before.

Alternatively, or additionally, scales may ask how severe symptoms are; there are many terms, not necessarily equivalent, used for severity, from ranked options from "mild" to "severe", to ratings of how distressing or disruptive each symptom is, again with ranked options (see table 7.2). This sort of scale may also be presented as a continuous scale, numbered or with just a line indicating distance, anchored at each end by the extremes, such as 'no pain' and 'worst possible pain'.

Table 8.2 Severity item from SF-36[32]

SF-36 pain item: How much bodily pain have you had during the past 4 weeks?	
None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

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30 Foa EB. Post-Traumatic Stress Diagnostic Scale Manual. National Computer Systems Inc., 1995.

31 Schwarz N. Self-reports: how the questions shape the answer, Amer Psychologist 1999;54:93-105.

32 Ware, J.E., Snow, K.K., Kosinski, M., and Gandek, B. (1993) SF-36 Health Survey: manual and interpretation guide, Boston, Health Institute, New England Medical Center.

Frequency and severity may also be mixed, as in table 8.3.

Table 8.3 Mixed frequency and severity item from Hospital Anxiety & Depression Scale[33]

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

Statements presented may be very close to symptoms, or may attempt to sample a more abstract concept. For instance, a depression questionnaire could offer statements representing increasing severity, as in the depression item from the BDI in Table 8.4. This is one of 21 items in the original BDI (Beck et al., 1961) [34], so that not everyone who meets diagnostic criteria will necessarily endorse one of the more severe statements here; it is the overall score which is important. Note also that there are two statements which score 2, implying that they are equal in severity.

Table 8.4 Severity ranked from Beck Depression Inventory[34]

0	I am not particularly pessimistic or discouraged about the future.
1	I feel discouraged about the future.
2	I feel that I have nothing to look forward to.
2	I feel that I won't ever get over my troubles.
3	I feel that the future is hopeless and that things cannot improve.

Scoring systems

The scores assigned to each answer may or may not be visible to the person answering the questionnaire according to the scale. In the BDI and HADS, for example, the scores are not visible, whereas on the SF-36 the respondent is asked to circle the score, not the item in words. Both require that after the questionnaire is completed, someone add the scores. Where scores are not shown on the questionnaire, a scoring key is needed. Complexities such as tied ranks (as in the BDI item above), reverse scoring, or weighting of items, all contribute to error in calculating the total score, and can make significant demands on staff time.

Technological solutions such as scanning paper questionnaires and scoring them are also error-prone, but increasing availability of mobile technology means that people can be presented with questions and response options on mobile phones and tablets, or at a desktop computer, with automatic scoring as described in section 6. That said, with torture survivor populations, and the settings in which they may receive services, these methods are likely to be unrealistic. Generally, computerised methods are seen as increasingly acceptable across ages and cultures (Wagner et al., 2010)[35], and can save staff time, though can also be experienced as insensitive, mechanistic and bureaucratic, particularly when faced with torture survivors in extreme distress.

Scores assigned to responses (such as those above) are effectively ranks. That is, they do not

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33 Zigmond, A.S., & Snaith, R.P. (1983) The Hospital Anxiety and Depression Scale, Acta Psychiatrica Scandinavica 67, 361-370.

34 Beck, A.T., Ward, C.H., Mendelson, M., Mock, N., and Erbaugh, J. (1961) An inventory for measuring depression, Archives of General Psychiatry 4, 561-571

35 Wagner N, Hassanein K, Head M. Computer use by older adults: a multi-disciplinary review. Computers in Human Behav 2010; 26:870-882.

have the same relationship to one another as real counts of events. For instance, if the number of nightmares in the last week was 4 and this week is 2, there is no doubt that this is a 50% reduction, but the change in a symptom score of 4 'at least daily' to 2 'sometimes' cannot be described in those terms. Well-constructed scales with multiple items, appropriate response options, and coherence of the items with the underlying construct, are often treated as if the scales represented real quantities of the concept, and statistically this is permissible. However, multiple-item scales mean that the same total score can be achieved by many different combinations of items and responses. A diagnosis of PTSD in the new DSM-5 could be achieved by over 600,000 different combinations of symptoms (Galatzer-Levy and Bryant, 2013)[36]. Additionally, relationships among scale items often differ from one population to another, for instance, with ethnic or age differences (Cliff and Keats, 2007)[37].

Additional considerations

Creating high standard questionnaires and testing them is a major undertaking, very expensive and often a commercial enterprise. Therefore, materials and evidence are not necessarily in the public domain, and the measure, the scoring manual, or a licence for use may need to be purchased. Informal creation of questionnaires, which is common, does not always attend to the conventions guiding clients' responses (Schwarz, 1999)31, or overestimates some threats (such as to reliability from the influence of social desirability) while overlooking more important ones (such as oversimplification, neglect of base rate, or lack of appreciation of cultural differences). Clinicians and researchers still frequently fail to involve the target population in the development of measurement instruments, to the detriment of all who subsequently use it.

Proxies or observers

Proxies or observers may be used rather than self-report for assessment. Clinicians or therapists, teachers, parents, or spouses/partners and family members can all be asked questions related to the individual in treatment. Although in the past clinician ratings and opinions have been given special status, sometimes even over the individual's own account, it is now appreciated that each of these people has a unique viewpoint which may well not coincide with the individual's.

Diagnoses

Diagnoses are a particular case of assessment, using trained skills and experience as well as materials such as diagnostic criteria or standard sets of questions. Meeting those criteria is often referred to as 'caseness'. Alternatively, data may be presented in terms of how many people in a sample were diagnosed as having the disorder in question; this can also be the outcome of questionnaires used diagnostically, having been standardised against such questioning. Data of this sort tend to be dichotomous, and of course while some people in treatment make substantial changes from 'caseness' to 'non-caseness', others who also move from 'caseness' to 'non-caseness' may change only by one or two points, often comparable with the standard error of measurement, and yet others may have begun treatment at the upper limit of 'non-caseness' and ended treatment in an essentially healthy state, yet without that change being evident from data presented dichotomously. On the whole, reliance on changes in 'caseness' to 'non-caseness' are a convenient short-hand but very problematic for reasons outlined above, and because they focus not on the range of outcomes of relevance to torture survivors; but instead focus on specific diagnoses, of questionable validity across cultures and diverse populations, relying on assumptions of discrete

36 Galatzer-Levy IR, Bryant RA. 636,120 ways to have Posttraumatic Stress Disorder. Perspec Psychol Sci 2013;8:651-662.

37 Cliff N, Keats JA. Ordinal measurement in the behavioral sciences. New Jersey: Lawrence Erlbaum Associates, 2007.

cut-off points which apparently distinguish between 'normal' from 'abnormal' psychological responses.

Summary of problems with outcome tools

In general, given the needs of services aiming to support rehabilitation and integration of refugees and asylum seekers, many outcome tools are narrow in focus, threatening their adequacy in the population of interest; have a very individual conceptualisation of problems focussing on deficit or dysfunction without context, or even on diagnosis; members of the target population are even less often involved as partners in development of the instrument than occurs in English-language medium ones; shortcomings in the strategies used to develop and test instruments in the target language are very common; and inadequate reliability and validity may pose a serious threat to sensitivity to change and meaningful interpretation.

8.8 Qualitative approach

Qualitative analyses use a variety of approaches, from informal description or reporting to more formal methods of analysis of content, themes, and associations (Joffe and Yardley, 2004[38]; Napoles-Springer and Stewart, 200622; Braun and Clarke, 2006[39]; Joffe, 2011[40]; Willig, 2001[41]; Harper and Thompson, 2012[42]). They allow more personalised responses, avoiding the constraints of checklists and questionnaires, but these responses have to be combined somehow, and much personal meaning may be lost in this process.

Approaches to collecting qualitative data vary and can include the use of open-ended questions on measures, using semi-structured interviews with individuals or groups, focus groups amongst many others. One of the simplest methods is to ask respondents to provide answers in their own words. For instance, one could assess needs by asking respondents for their three most important concerns. But faced with two people's responses of "no home, worry about children, don't feel safe" and "my children, no money, accommodation", how is the assessor to summarise this? Are the concerns about children the same: might one respondent not know where her children are since she fled, while another is concerned about the welfare of children living with her? And can it be assumed that the first has no financial problems, and the second feels safe? Any written answers have to be grouped and interpreted making these assumptions or guesses and thus may seriously under-represent problems because they are not mentioned.

If a response is elicited during interview, the interviewer can probe and clarify in order to ensure more satisfactory coverage of the area of assessment. Interviews can be recorded and transcribed and subjected to qualitative methods of analysis (Joffe and Yardley, 2004)38 to summarise them, for instance, in terms of themes (Braun and Clarke, 2006)39. Competent analysis not only stays close to respondents' own descriptions, even to the words and phrases they use, but elicits meta-level meaning and associations (Braun and Clarke, 200639; Harper and Thompson, 201242) which can bring real insights. Qualitative methods provide rich data and insights, but they are time-consuming and, again, automated analytic methods have been developed (e.g. NUDIST, Atlas. ti) which facilitate analysis but are no substitute for the interpretation of the data. Qualitative

38 Joffe H, Yardley L. Content and thematic analysis. In Marks DF, Yardley L. (eds). Research methods for clinical and health psychology. London: Sage, 2004.

39 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psy 2006; 3(2): 77-101.

40 Joffe H Thematic Analysis. In Harper D, Thompson AR (eds.), Qualitative Research Methods in Mental Health and Psychotherapy. Wiley-Blackwell 2011, pp. 209 - 223

41 Willig C. Introducing qualitative research in psychology. Buckingham: Open University Press, 2001.

42 Harper D, Thompson AR. Qualitative research methods in mental health and psychotherapy. Chichester: Wiley-Blackwell, 2012.

methods, like all research methods, require appropriate knowledge and competency.

8.9 Organisation context of evaluation

Many of the comments in sections 6 and 7 apply equally here. Staff and managers have a significant contribution to make in setting overall goals and priorities, as described in Purposes of evaluation above and in sections 6 and 7. Sharing ideas about success, failure, 'good enough' and 'not good enough' outcomes; reviewing 'near misses' and serious problems and discussing the assumptions implicit in administrative and clinical practices (such as policies of discharging people after they miss two successive appointments), are all useful exercises in themselves: they also provide the framework and broad content for evaluation. It is further helpful to clarify what demands evaluation will make, and on whom, since underestimation of necessary resources and subsequent inability to meet demands is a common reason for the failure of evaluation.

Reluctance to discuss and engage in evaluation is not uncommon, and is often related to fears of comparison of clinical staff and 'league tables' of outcomes, fears often based on widespread practices in commercial settings of judging, rewarding, or dismissing staff according to productivity. There may also be fears that collectively, rather than individually, services will be found lacking. Staff can be reassured that it is important to know shortcomings in services provided, and to identify ways to improve the situation, to better serve torture survivors.

Beyond that, the duty of accountability to clients, to professionals who refer to the services, and to those who fund it directly or indirectly, is surprisingly rarely invoked. Outside medicine, and particularly outside health and welfare professions which are registered and subject to professional scrutiny and discipline, there is little or no regulation of quality of practice, and goodwill or good intention are erroneously assumed to guarantee efficacy. This is not to assert that good outcomes come only from interventions by trained professionals, but commonsense or lay beliefs can lead to harm as well as to benefit. A good example of this is crisis teams of volunteers who descend on populations following a disaster to provide 'psychological debriefing'. Such early intervention has been found to be, on average, detrimental to those involved in the disaster, who are better left to their own ways of recovering, with help offered only to those still struggling to recover weeks later (see McNally et al., 2003[43]; Lilienfield, 2007[44]). Yet the practice continues.

8.10 Deciding what to evaluate

The choice of domains of measurement is addressed above, in 8.4.

Only pilot testing will establish how long and detailed an assessment clients are willing to undergo. Overlong or repetitive, overlapping instruments will reduce reliability by producing fatigue, boredom, and frustration in respondents. The compromise between wanting to spread the net wide to capture any progress or achievements made by clients and wanting to avoid undue burden or refusal is a difficult one.

Developing/deciding evaluation tools to use

There is a large choice of assessment instruments and, though new ones are always appearing, a very useful resource for established ones is the volume by McDowell (2006)27 which describes and evaluates these. Descriptions of the populations on which instruments were developed and standardised, and examples of their content or reproduction of the entire measure, is enormously

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43 McNally RJ, Bryant RA, Ehlers A. Does early psychological intervention promote recovery from posttraumatic stress? Psychol Science Public Interest 2003;.4:45-7944 Lilienfield SO. Psychological treatments that cause harm. Persp Psychol Science 2007; 2:53-70.

45 Derogatis LR. The SCL-90R manual-II. Baltimore: Clinical Psychometric Research, 1983

helpful in judging suitability for the clients (with particular attention to avoiding floor and ceiling effects), and suitability for the purposes of the evaluation. We draw here on those used in randomised controlled trials of treatment of torture survivors and which performed adequately in a relevant population (Patel et al., in press)6, selecting only those which can be completed by self-report (rather than by a clinician interview), plus a few in widespread use in current mental health services. Jaranson and Quiroga5 (2011: Table 3) provide a longer list from unpublished sources of instruments in use in projects offering services to torture survivors, as does Hollifield et al. (2002)15 from published sources.

Below are several tables and associated text on domains of measurement and candidate instruments, for adults, children and adolescents, and for family and community level intervention and measurement. They are taken largely from treatment trials with high methodological quality where they were used to identify changes in survivors of torture or of organised violence.

Mood / distress in adults

Mood, distress, and psychological problems are addressed either by broad scope diagnostic measures administered by a clinician or trained interviewer, following up in detail areas where the interviewee indicates problems, or by self-report questionnaires which are often narrower in scope. Only the self-report instruments are listed in Table 7.5, and the Symptom Checklist 90 (SCL-90-R)[45] is excluded because, although it is self-report, much of the content of the nine subscales of different psychopathologies is irrelevant to most clients.

Widely used in clinical settings in the UK but so far not extensively in studies of refugees is the CORE (http://www.coreims.co.uk). Widely found in the research literature but not recommended for service evaluation are the Hamilton Depression Scale (Hamilton, 1960)[46], and the Hopkins Symptom Checklist (HSCL-25)[47]: these require completion by a trained clinician, a resource beyond most routine services.

The instruments for self-report of mood and distress draw predominantly on the same criteria as those informing diagnostic measures. They tend to contain somatic items which are assumed to be related to mood (such as lack of energy, lack of appetite, etc.) but which can be attributable to physical disorders, diagnosed or not. Care is required here in considering, or asking the respondent, the reasons for endorsement of physical symptom items. The only instrument

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46 Hamilton M. A rating scale for depression. J Neurol, Neurosurg Psychiatry 1960; 23:56-62.
47 Derogatis LR. Administration, scoring and procedures manual. Baltimore: Clinical Psychometric Research, 1983.

Table 8.5 Mood and distress measures for adults

Name	Content	Minutes to complete	Availability
Beck Depression Inventory BDI – I, BDI-II[48]	Intensity of 21 symptoms	10-15 BDI 5-10 BDI-II	Buy from www.pearsonclinical.co.uk/
Beck Anxiety Inventory BAI[49]	How much bothered by 21 symptoms	5-10	Buy from www.pearsonclinical.co.uk/Free
Hospital Anxiety and Depression Scale HADS[50]	Severity of 7 anxiety + 7 depression symptoms = distress	5	
General Health Questionnaire GHQ[51] 12, 28, 30 item	Presence and severity of symptoms compared to usual. Overall distress	5-10	Buy from http://www.gl-assessment.co.uk/products/
versions most used Mental health subscales of SF-36 and SF-12[52]	Impact of emotions on everyday activities	5-10	Buy from http://www.sf-36.org/
Self-Report Questionnaire SRQ-20[53]	20 symptoms of anxiety, depression, common physical symptoms: response yes/no	5	Download free from WHO whqlibdoc.who.int/hq/1994/WHO_MNH_PSF_94.8.pdf

designed to be free of somatic symptoms is the HADS (see table 8.5).

However, while the dominant models of depression in Western populations are biological, lifestyle (stress), or a mix of the two, other populations may view 'symptoms' within a framework of situational problems for which there may be multiple non-medical and non-psychiatric solutions (Karasz, 2005).

48 Foa EB, Riggs DS, Dancu CV, Rothbaum BO. Reliability and validity of a brief instrument for assessing post-traumatic stress disorder. J Traumatic Stress 1993;6:459-473. http://www.istss.org/PosttraumaticSymptomScaleInterviewVersion.htm

49 Bowling A. Measuring health, 2nd edition, Buckingham: Open University Press, 1997.

50 Boynton PM, Wood GW, Greenhalgh T. Reaching beyond the white middle classes. Brit Med J 2004;328:1433-1434.

51 Foster SL, Mash EJ. Assessing social validity in clinical treatment research: issues and procedures. J Consult Clin Psychol 1998; 67:308-319.

52 Stenner PHD, Cooper D, Skevington SM. Putting the Q into quality of life; the identification of subjective constructions of health-related quality of life using Q methodology Soc Sci Medicine 2003; 57:2161-2172.

53 Gladis MM, Gosch EA, Dishuk NM, Crits-Cristoph P. Quality of life: expanding the scope of clinical significance, J Consult Clin Psychol 1999; 67:320-331.

Table 8.6 Traumatic stress scales for adults

Name	Content	Minutes to complete	Availability
Impact of Events Scale IES, revised IES-R[54]	22 items: how distressing events are on 5 point scale from not at all to extremely: scored as subscales intrusions, avoidance, hyperarousal.	5-10	Buy from http://getcbt.org/download/r-ies.pdf
Harvard Trauma Questionnaire HTQ[55]	Part 1: degree to which traumatic events were experienced (4 point scale). Part 2: torture experience. Part 4: symptom severity: 16 general items + 14 culture-specific items severity scored 4 point scale, not at all - extremely.		Buy from http://hprt-cambridge.org/screening/harvard-trauma-questionnaire/
Post-traumatic Diagnostic Scale PDS[56]	Parts 1 & 2 most important traumatic events experienced Part 3 frequency of 17 intrusive thoughts and sensations, on 4 point scale from never to nearly always. Part 4 interference by these symptoms with 9 areas of life.	10-15	Buy from http://www.pearsonclinical.com/psychology/products/100000441/posttraumatic-stress-diagnostic-scale-pds.html

The trauma scales mix quantification of traumatic events (a criterion for diagnosis) and current symptoms. Several have diagnostic cut-off points as well as scoring on continuous scales. An additional scale related to the PDS, the Post-Traumatic Stress Scale (PSS-1: Foa et al., 1993)[57] is given by interview, not self-report, so is not recommended here.

Function / participation / goal achievement / quality of life in adults

This large category ranges from collections of items about performance of particular tasks (from self-care to paid work) to quality of life measures with their broad sampling across social, psychological and other domains of activity. Many require an assumption of what is a normal lifestyle, although this may not be accessible to or possible for refugees and other torture survivors.

A significant shortcoming of most measures is that they draw largely on health professionals' definitions of what is normal or desirable (Bowling, 1997[58]; Boynton et al., 2004[59], Foster and Mash, 1999[60]). Although the instruments mostly attempt to incorporate the subjective experience of respondents, there has been too little involvement of potential respondents in the development of many, and, arguably, an instrument which aims to measure objectively can never represent subjectivity adequately (Stenner et al., 2003[61]). Until recently, there has been little development

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54 Hyland ME. A reformulation of quality of life for medical science, Qual Life Res 1992; 1:267-272.

55 Dybdahl R. Children and mothers in war: An outcome study of a psychosocial intervention program. Child Development 2001; 72(4):1214-1230.

56 Wolff PH, Tesfai B, Egasso H, Aradom T. The orphans of Eritrea: a comparison study. J Child Psychol Psychiatry Allied Disciplines 1995; 36(4):633-644.

57 Bates L, Baird D, Johnson DI, Lee RE, Luster T, Rehagen C. Sudanese refugee youth in foster care: the "lost boys" in America. Child Welfare 2005; 84:631-648.

58 Hodes M, Jagdev D, Chandra N, Cunniff A. Risk and resilience for psychological distress amongst unaccompanied asylum seeking adolscents. J Child Psychol Psychiatry 2008; 49(7):723-732.

59 Panter-Brick C, Eggerman M, Gonzalez V, Safdar S. Violence, suffering, and mental health in Afghanistan: a school-based survey. Lancet 2009; 374:807-816.

60 Papageorgiou V, Frangou-Garunovic A, Iordanidou R, Yule W, Smith P, Vostanis P. War trauma and psychopathology in Bosnian refugee children. Eur Child Adolesc Psychiatry 2000; 9:84-90.

61 Ehntholt KA, Yule W. Practitioner review: assessment and treatment of refugee children and adolescents who have experienced war-related trauma. J Child Psychol Psychiatry 2006; 47(12):1197-2010.

of theory or research on what quality of life means (Bowling, 1997[58]; Fitzpatrick et al., 1998[14]; Gladis et al., 1999[62]): the same overall construct, such as social support, may have very different meanings for people in different situations and with different options and preferences. This makes validation and estimation of responsiveness to change very difficult (Terwee et al., 2003).

The broader the content (including, for instance, feelings about the environment, or spirituality), the more users need to ask which aspects they realistically expect to change with treatment: for instance, an effective treatment for post-traumatic stress symptoms might or might not change the individual's evaluation of his or her social relationships or his or her overall health. The sensitivity to change of the SF-36 has been questioned on this basis (Bowling, 1997). Those questionnaires which take the broadest view of quality of life may seem to the user to be idiosyncratic in their choice of items, or those items may apply very poorly to the population of concern, and the need to add all domains into a single numerical total is hard to justify (Hyland, 1992)[63]. Comparison of instruments shows widely differing content even within the same domain (such as social activity) and it can be hard to find an instrument which samples adequately in areas of relevance (Bowling, 1997).

Table 8.7 Quality of life scales for adults			
Name	**Content**	**Minutes to complete**	**Availability**
Medical Outcomes Study SF-36, SF-12[64]	36 or 12 questions on severity and impact of physical and mental health problems, and general health. Requires manual for scoring. Provides population norm scores.	10 (SF-36) 5 (SF-12)	Buy licence and materials from http://www.sf-36.org/ http://www.qualitymetric.com/ also for manuals and forms
WHO Quality of Life WHOQOL-BREF[65]	24 items physical and psychological health, social relationships, environment.	5	Permission from WHOQOL@who.int
Quality of Life Inventory QOLI[66]	17 areas of life: importance on a 3 point scale and satisfaction on a 7 point scale, combined for total score.	5	http://www.pearsonclinical.com/psychology/products/100000635/quality-of-life-inventory-qoli.html
GHQ 60 item version[67]	See distress scale: this version also has items on wellbeing.	10-15	Buy from http://www.gl-assessment.co.uk/products/

62 CO-OP Group: Children and Young People's IAPT Outcomes-Oriented Practice Group. A practical guide to using service user feedback and outcome tools to inform clinical practice in child and adolescent mental health. www.iapt.nhs.uk/silo/files/a-practical-guide-to-using-service-user-feedback--outcome-tools-.pdf

63 Duncan J, Arntson L. Children in crisis: evaluating psychosocial programming. Save the Children Fund, 2007.

64 Timimi S, Tetley D, Burgoine W, Walker G. Outcome orientated child and adolescent mental health services (OO-CAMHS): a whole service model. Clin Child Psychol Psychiatry 2013; 18:169-184.

65 Michelson D, Sclare I. Psychological needs, service utilization, and provision of care in a specialist mental health clinic for young refugees: a comparative study. Clin Child Psychol Psychiatry 2009; 14:273-296.

66 Borgatti SP, Mehra A, Brass DJ, Labianca G. Network analysis in the social sciences. Science 2009; 323(5916):892-895.

67 Groark C, Sclare I, Raval H. Understanding the experiences and emotional needs of unaccompanied asylum-seeking adolescents in the UK. Clin Child Psychol Psychiatry 2011; 16:421-4442.

Specific goals

If there are particular goals which are important targets of intervention (such as enrolling in an English class, or navigating public transport, for instance) but not included in function or quality of life instruments, they are best addressed using single questions, and these need to be designed bearing in mind the issues raised above in 8.6. Particularly in the difficult circumstances in which many refugees find themselves, it cannot be assumed that steady progress in one area or in overall quality of life implies progress in related areas or specific goals.

Evaluation of interventions with children

Children are likely to express distress and disrupted development behaviourally as well as (or rather than) through self-report, so observational measures are more important here than with adults. We took the same approach as for adult instruments, of searching for trials of interventions with survivors of torture and organised violence to see what instruments had shown effects. However, this was less useful since there were very few trials eligible, and they used cognitive testing which is not recommended, or older instruments for which we could find no or rare later use (Dybdahl 2001[55]; Wolff et al. 1995[56]; Bates et al. 2005[57]). We therefore consulted UK intervention studies with this group (Hodes et al. 2008[58]; Panter-Brick et al. 2009[59]; Papageorgiou et al. 2000[60]), clinicians working in the area, and reviews of assessment instruments of relevance (EBPU, Ehntholt & Yule 2006[61]; CO-OP group 2012[62]). We also describe more qualitative approaches.

Table 8.8 Mood and distress (including posttraumatic stress) instruments for children			
Name	**Content**	**Minutes to complete & age**	**Availability**
Moods & Feelings Questionnaire MFQ	33 items on depression: affective, cognitive, and physical symptoms. Responses to each: true, sometimes, not true. Single total.	5 minutes 7-18 years	Download free with permission from https://devepi.duhs.duke.edu/mfq.html
Revised Child Anxiety & Depression Scale RCADS	47 or 25 items on anxiety. Responses: never, sometimes, often, always. Produces totals for anxiety and for internalising.	5-10 minutes 8-18 years	Download free with scoring system from http://www.childfirst.ucla.edu/Resources.html
Children's Revised Impact of Events Scale CRIES-8	8 items covering intrusion and avoidance; response on 4 point scale from not at all to often.	5 minutes Self-report from 8y	Download free from www.childrenandwar.org/measures
Strengths & Difficulties Questionnaire SDQ	5 behavioural domains: conduct, hyperactivity, emotion, peer relationships, prosocial behaviour. Response on 3 point scale of how true of child.	5 minutes 11-16y self-report; 3-16y parent/teacher completion	Download free from http://www.sdqinfo.com/a0.html

Reviews are less likely to address measurement in children, and adolescents are frequently assessed with adult instruments, even though their age group may not have been included in standardisation. The summary by Duncan and Arntson (2003) of psychosocial interventions is very helpful here in identifying the context of therapeutic interventions with children, and that they do not necessarily involve direct work with children themselves, but with their parents, with

whole families, and with the community. Another valuable resource, even though not written with this client group in mind, is the summary of measures of mental health outcomes compiled by the Evidence-Based Practice Unit of the Child and Adolescent Mental Health Services of UCL and the Anna Freud Centre (www.annafreud.org/ebpu).

There are also scales in development which ask a child for his or her ratings, on a visual analogue scale (a line representing a scale between a negative anchor at one end and a positive anchor at the other) of overall outcome in terms of 'how things are going' in family, school, and 'everything', and session outcome in terms of being listened to, discussing important issues, liking the content of the session, and overall rating: see www.oocamhs.com for the tool and to buy the licence.

Additionally, it can be useful to ask a child or young person for feedback on the process of the therapeutic session, using questions such as: what did you like about the session; what did you not like; how useful was the session; would you recommend it to your friends; did it help you with [target of intervention]; did you feel that the therapist was interested in you; (for groups) did you feel that the others in the group were interested in you; etc.

Quality of life for children

This area is less well-developed for children and young people than for adults, and often completed by a parent or caregiver. Additionally, we found no instruments in the studies or reviews which addressed family functioning, although that is important for those children and adolescents who still have family around them or are in the care of a family, and it may be the primary target of intervention. One scale in reasonably common use in the UK, including in work with refugee children is the Paediatric Quality of Life Enjoyment and Satisfaction Form (PQ-LES-Q; Endicott et al, 2006).

Table 8.9 Quality of life measures for children			
Name	**Content**	**Minutes to complete & age**	**Availability**
Psychological Sense of School Membership PSSM	18 items about involvement in and beliefs about school; responses on 5 point scale from not true at all - completely true.	5-10 minutes 12 years upwards	Reproduced in references (see footnote)
Paediatric Quality of Life Enjoyment and Satisfaction Form PQ-LES-Q	15 items. Responses on a 5 point scale: very poor, poor, fair, good, very good. 14 items make total; 1 item is overall.	5-10 minutes 6-17years	Reproduced in reference (see footnote)

An alternative to a self-report instrument is to use specific questions pertinent to the child's or adolescent's situation and experience, including protective factors. Although it focuses particularly on psychological diagnoses, the review by Ehntholt and Yule (2006) also lists the difficulties of somatic complaints, sleep problems, and peer relationship problems, and notes the potential importance of family separation, belief systems, social support, and the post-migration stresses to which adults are also subject.

Since there are fewer instruments in common use and well-tested than in adult research, some may not transfer well from the particular population in which they were developed and used. In that case it is preferable to use checklists and specific questions which are of direct relevance to

the population of concern or to the needs assessment. Information on a particular problem area gathered through self-report or an interview can be quantified: a study of psychological needs and service use among young refugees (Michelson and Sclare, 2009)65 has examples of combining and quantifying information gathered by the clinician: about refugee children's living conditions for a social support score, and about traumatic experiences combined as a total of number of different types.

Community function

Although there are several trials of diverse interventions to work with communities affected by humanitarian and human rights violations, outcomes were measured either with individual scales (symptoms, diagnoses, etc.) or in terms of user satisfaction. Neither of these, while they might represent worthwhile outcomes, assesses changes in individuals' feelings about and experience of their community, of interrelationships, and of belonging. It is possible that some of the tools of social network analysis (Borgatti et al., 2009)66, which identifies groupings within large cohorts and individuals' connectedness within the grouping/s, will offer methods to analyse changes within communities, but they currently require specialist help and software.

Qualitative methods

Qualitative methods can offer deeper, richer and more client-centred understandings, both of general and particular problems and experiences of torture survivors than quantitative assessments. Like quantitative methods, qualitative methods also require relevant knowledge, skills and resources which may not be available to most services.

The following example is from a study of young refugee people. Following review of consistent findings of psychological distress and disturbance, but also of the critical literature on reducing these problems to diagnoses, Groark et al. (2011)67 aimed to capture information in its context and in refugees' own terms. For these reasons, they used qualitative methods to study young people's experience of the asylum process in the UK, how past experience impacted on their psychological wellbeing, and how the young people dealt with their problems. They analysed the interview data (interpreted where necessary) using recognised methods which elicited themes of loss, of negotiating a new way of life, distress, and adjustment. Such findings can guide better design of assessments, as well as service provision.

8.11 Summary

The selection and use of clinical outcome evaluation tools is not possible to summarise as a brief 'how to' list or recipe. To be useful, clinical outcome evaluation needs to be embedded in the organisation, in its aims and methods, and in its day to day practice. The difficulty of the task for those not trained in it, and the resources required, are a significant deterrent. But the option of using only routine monitoring and broad service evaluations and simple client feedback at planned end of intervention is inadequate. To make advances in the field resources are required for further research and tool-development.

In wishing to evaluate and improve rehabilitation services, organisations need to invest, and collaborate, in seeking ways to evaluate services against a range of quality standards, including effectiveness.

9. Reporting to donors

Implementing monitoring and evaluation systems for rehabilitation services is a huge undertaking. As noted in earlier sections, there are many reasons for conducting monitoring and evaluation but foremost to enable services to be accountable and to ensure the highest quality of services for torture survivors and their families. Donors, like service providers, share this goal.

This section describes considerations in reporting to donors on monitoring and evaluation.

9.1 Donor requirements

Most rehabilitation services, if not solely state-funded, are funded by a range of donors over different periods of time. Funding for rehabilitation services for torture survivors is relatively limited and even diminishing, while pressure is increasing for states to ensure sustainable funding, as is their legal obligation, for rehabilitation services. In the current context, where advocacy to ensure states meet their obligation is mostly met with silence, the need for rehabilitation services to survive is greater than ever. Monitoring and evaluation reporting requirements may be seen as cumbersome, requiring more time than is available and more effort than can be afforded with limited and diminishing resources. Yet, without reporting to donors, resources will not be maintained and services cannot be sustainable.

It is important that service providers understand what donors require by way of information about the services, and why.

The nature of reporting to donors will depend on many factors, summarised in Box 14.

Box 14: Factors relevant to reporting to donors

- Type of funder
- Nature of grant (e.g. restricted and project-focused, core, short-term, medium-long-term; independent or tied to match-funding)
- Size of grant
- How donors deliver their grants (e.g. instalments based on reports)
- Frequency of reporting required (e.g. six-monthly, annual, grant instalment-related)
- Ramifications of not reporting (e.g. grants being recalled, ended or not renewed)
- Nature of donor requirements: narrative reports, quantitative information, target-driven achievements, milestones towards targets, information on outputs and outcomes etc.
- Donor requirements for monitoring and evaluation systems in the organisation
- Nature of challenges to effective delivery of services/reporting as required
- Nature of relationship and communication between donors and grantees
- Donor's knowledge and understanding of the field
- Donor's awareness and appreciation of the unique local, political, legal, social, economic and cultural context of the rehabilitation service

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Essentially, donors understand the complexity of reporting and that it requires time and skill. They also generally understand that monitoring and evaluation of rehabilitation services for

torture survivors is not comparable to other areas. They are aware that with torture survivors, their needs are complex, multi-level, simultaneous and changing, often ranging from immediate crisis care to longer-term empowerment, with vocational, educational and occupational initiatives to facilitate integration into society. Donors are aware that service provision for torture survivors often focuses on their health and legal protection needs as paramount, and that the context of providing services is uncertain, sometimes unsafe, and almost universally under-resourced with demand far outstripping supply.

Donors for organisations may change from time to time. Donor priorities may be different, and their focus for monitoring and evaluation may be different. The implications for monitoring and evaluation and for reporting to different donors may be significant. Donors will be more or less familiar with the field and some will not be aware of all the factors which may impact on reporting. It is essential that a relationship be established between donors and grantees where communication which is frequent and as accurate as possible can be nurtured.

Good practice includes:
- Know who your donors are
- Help donors to know your service and its unique context which determines service design and delivery
- Identify donor requirements for reporting: what is needed, in what form, when, how, why?
- Establish how donor requirements can be met with existing monitoring and evaluation systems in the organisation
- Identify how these systems within the organisations need to be adapted or complemented to meet donor requirements
- Establish what is most important to communicate to donors, where reporting requirements cannot be wholly met
- Inform donors as soon as possible what the challenges or obstacles to reporting are
- Inform donors what steps are being undertaken by the organisation to ensure that appropriate and effective monitoring and evaluation systems are in place (see Section 3)

9.2 Donors as partners

Donors are effectively partners working towards the same goals as service providers – the provision of high quality services for torture survivors and their families. Donors want what service providers want – to realise the right to appropriate rehabilitation for torture survivors and their families.

Unfortunately, under the pressure of heavy workloads and limited and decreasing resources, service providers feel resentment against donors for imposing what may seem like unrealistic, numerous and different demands for reporting. It is important to remember that reporting obligations to donors is not the sole rationale for monitoring and evaluation. Rather, these are a shared exercise to ensure high quality rehabilitation services. An important role for donors is to encourage organisations to establish systems for meaningful, ethical and effective monitoring and evaluation and to support them in reporting on these as effectively as possible. This works best when there is effective communication and trust between donor and grantee.

Unfortunately, poor reporting can lead to donors becoming frustrated at not knowing how effectively the grants are being used and what their impact is on the wellbeing and rehabilitation of torture survivors. The ramifications of poor reporting and poor communication with donors is that they may simply not renew grants. Further, donors may change their priorities for areas they

will fund in the future, affecting the whole field.

Donors face many challenges in providing funding in this field. Often, they are not specialists in multidisciplinary rehabilitation of torture survivors, a complex, multifaceted field. They rely on service providers to provide clear information, rationale for their work and accountability for the quality of services provided.

In the absence of agreed standards for rehabilitation, until the recent landmark establishment of General Comment 3 of the United Nations Convention Against Torture, donors relied on general monitoring ('activities') and on some general criteria of quality services, most typically 'effectiveness' and impact'. Donors usually wish to understand better the work provided by rehabilitation services and to get an answer to the question 'Do the services provided help torture survivors and how?' The onus is on both donors and service providers/grantees to refine this question and its answers so that there is a better and shared understanding of whether and how services help ensure 'as full rehabilitation as possible' (as defined in international law) of torture survivors.

Good practice includes:
- Establishing good relationships with donors
- Understanding that donors are supporting partners in helping to ensure high quality services for torture survivors
- Providing monitoring and evaluation information, alongside the quality criteria for services. Use both quantitative and qualitative (narrative, case studies etc.) approaches in reporting, wherever possible
- Ensuring clear communication with donors, avoiding ambiguity where there are obstacles to reporting on the use of grants
- Ensuring honest communication with donors: respond to their questions frankly
- Donors want to know exactly what is happening and to understand why
- Ensuring that monitoring and evaluation systems are not only a vehicle for reporting to donors, as this can lead to shortcuts and unethical decision-making, compromising client care and the quality of services
- Ensuring that data from torture survivors is collected in accordance with the highest ethical principles (informed consent and confidentiality), and that data integrity is ensured. Reporting is meaningless and unethical if the content is established through unorthodox and unethical means of collecting, recording and analysing data.

9.3 Types of donor questions

The types of questions donors ask varies, as noted in Section 9.1, according to the donor, their focus, organisational priorities etc. The broad types of questions which donors ask in relation to monitoring an evaluation, are summarised in Box 15.

- **Organisational aims:** What is the organisation's monitoring and evaluation framework? Is it clear about services provided, goals of services and aims of the organisation?
- **Activities:** What are the activities conducted by the organisation and how extensive are they?
- **Achievements:** What do the services achieve?
- **Outcomes and impact:** What are the anticipated and unanticipated outcomes and the impact of the services provided?
- **Challenges and learning:** What challenges have been faced by the service and what has been learnt during the grant period (e.g. in relation to service delivery, activities offered etc.)
- **Other information:** This provides an opportunity for the organisation to report on activities /events which do not easily fit in other areas of reporting

Sometimes, the questions may appear to overlap and seem to be asking for the same information in different ways. It is important to clarify what donors are actually looking for and why.

Sometimes there is a lack of clarity from donors on exactly what is meant in their questions. For example, how are 'outcomes' and 'impact' distinguished? Or how are 'achievements' different from 'outcomes'? It may be that some donors interpret those terms differently from comparable concepts in, say, healthcare aspects of rehabilitation. For example, the term 'outcomes' can be broadly understood by donors as referring to organisational outcomes and to individual client outcomes. In healthcare, outcomes may refer specifically to 'clinical outcomes' (sometimes referred to as 'treatment outcomes' because they refer to outcomes following healthcare treatment/interventions). In the field of rehabilitation for torture survivors however, as noted in Section 4, interventions can range from healthcare, social care, legal support, vocational guidance, community engagement and support etc.; and, as noted in Section 7, outcomes can range from 'clinical outcomes', context outcomes, functioning outcomes, legal outcomes etc.

When faced with more than one funder for a particular rehabilitation service:

Good practice includes:
- Clarify exactly what donors mean by terms they use (e.g. outcomes) and whether there is a preferred method or common indicators accepted by the donor as indicative of those outcomes.
- Identify all questions asked by donors and any commonalities in those questions
- Identify which quality criteria the questions refer to
- Identify how this information can be obtained
- Identify different ways in which this information can be measured, if it is not already being measured
- Revise the organisational monitoring and evaluation systems, where necessary, to accommodate additional information, not already collected, as required by donors
- Identify how this information can be reported meaningfully to the donor

Examples of the types of rehabilitation service-related information donors may require are summarised in Box 16:

Box 16: Sample of questions and information which donors request

- **Clients seen and provided rehabilitation**
  - Numbers of clients seen (new)
  - Numbers of clients currently provided rehabilitation (ongoing)
  - Languages spoken by clients
  - Demographic information on clients (gender, age, legal status, nationality, sexuality, ethnicity)
  - Types of torture experienced
  - Impact/sequelae of torture
  - Perpetrators
- **Rehabilitation services/activities agreed**
  - Nature of activities/services
  e.g. 'Outline if/which of the activities have been carried out within the grant period'?
  e.g. 'Provide a brief description of your centre's overall activities; as well as those activities supported by this grant'
  - Type of services/assistance/interventions
  - Number of rehabilitation sessions provided
  - Unit costs of rehabilitation sessions
  - Average duration of rehabilitation
  - Improvements or impact of rehabilitation
- **Project-related questions** against objectives agreed at the outset with the donor e.g.:
  - 'What are principal achievements in relation to objective 1?' or
  - 'What are shortfalls in relation to objective 1?'
- **Project outcome-related questions** where the outcomes and milestones of a service are agreed with the donor in advance e.g.
  - 'Briefly report on progress towards each of the outcomes you have identified in your project proposal, identifying progress towards milestones and outputs'.
- **Open-ended questions** to provide a narrative summary for any of the above
- **General questions** such as:
  - 'Please describe the significant achievements, successes and challenges over the last 12 months?'
  - 'Has the grant enabled your centre to enlarge the scope or improve the quality of services offered? Please explain and list measurable results.'
  - 'What has your team/organisation learned during the implementation and evaluation of your project?'
  - 'Having reviewed your progress over the last 12 months, do you intend to do anything differently over the next year?'
  - 'If this is your final progress report, explain how your target group's situation has improved and describe what impact your project has had?'

9.4 Donor monitoring of grants

Once grants are given, donors will monitor grants at different periods, with requests for interim, annual and final reports. The nature of monitoring, as mentioned earlier, will depend on different donor requirements, priorities and resources available for such monitoring.

Most donors do allocate staff resources to monitor grants and review reports provided by grantees, though this is usually very limited. Some also have resources allocated to organise and

conduct pre-screening and monitoring site visits. Many donors provide support to grantees on reporting via email and telephone discussions, and some may offer training through an independent organisation on generic aspects of monitoring and evaluation.

Donors face many challenges in ensuring effective reporting by grantees. Apart from limited resources, both for donors and service providers, specifically for monitoring and evaluation, the breadth of services donors may fund is itself a challenge. Some donors may have a global remit and fund many diverse organisations. Others may fund services within broad remits (e.g. asylum seekers and refugees) where services may serve torture survivors but not as their main client group.

Another challenge donors face is funding several organisations providing similar services but which conduct different levels and types of monitoring and evaluation. In the absence of agreement on standards for rehabilitations services and of agreed indicators of different aspects of service quality, the task for donors is daunting and confusing.

Donors also experience the lack of or limited information on the impact of rehabilitation, and outcomes of rehabilitation, a challenge. Some donors may require specific information on clients (e.g. minority groups, such as clients who are lesbian, gay, bisexual or transexual, clients from particular political or ethnic backgrounds) or on perpetrators. Such information may be very difficult for service providers to collect reliably and to report on.

Donors may monitor grants closely, via reporting mechanisms, regular telephone communication, requesting peer reviews or conducting site visits (perhaps meeting managers, practitioners, clients), but may not have specialist knowledge or support to effectively appraise the content of reporting on quality criteria of services. If grantees are tempted to submit reports which are vague or lacking in rigour, the process of reporting, and of monitoring and evaluation then risks being little more than a paper exercise. Neither donors nor service providers would agree that this is satisfactory or ethical. It is therefore incumbent on both to communicate exactly what is required, what it is possible to report on properly, and the reasons why. For donors, it is essential to know what steps are being taken by the organisation to ensure that monitoring and evaluation will be effectively implemented.

Good practice includes:
- Using a range of methods to report on rehabilitation activity, including using quantitative and qualitative information, narratives and case studies (of both positive outcomes and cases where outcomes were not always positive, or complex and contradictory)
- Communicating regularly and clearly with donors to facilitate monitoring. The more they understand the obstacles and challenges, and both anticipated and unanticipated outcomes, the more monitoring can be tailored to this field
- Letting donors know what steps are taken by the organisation to improve monitoring and evaluation and, if none, explain why
- Sharing insights on challenges and successes in service delivery with donors – they are keen to learn, to increase their knowledge and understanding of the field and to improve their monitoring processes

9.5 Closing reflections
The field of rehabilitation for torture survivors faces many challenges, not least the financial sustainability of those scarce specialist services in high demand. Both donors and service

providers are aware of this. One challenge is developing meaningful and realistic monitoring and evaluation, in ways which address donors' concerns about the quality of reporting on rehabilitation by service providers; and service providers' concerns about what may seem to many as unrealistic and onerous demands from diverse donors. Service providers face numerous challenges with respect to monitoring and evaluation; these include engaging and motivating beleaguered staff; lack of resources; and lack of appropriate expertise to conduct monitoring and evaluation. Even for those with expertise, there are many theoretical and methodological challenges in the field.

It is no doubt evident from this guidance that further work in critical areas is still needed. The future of this field and the likelihood of the effective implementation of the right to rehabilitation for torture survivors, depends on concerted, collaborative efforts between all parties, service providers, donors and states. Without financial support for service delivery and for the advances necessary in this field, the right to rehabilitation for torture survivors is likely to be little more than an abstract ideal, a right without teeth.

Glossary

Evaluation Systematic assessment of change in an individual, group, practice, activity, project or service

Impact A short, medium to long-term effect of an activity, intervention or service. Impact can be on individuals, families, communities, organisations, stakeholders, society, policy, practice, structures etc. Impact can be any change, positive or negative; anticipated or unanticipated; intended and unintended. Impact is change at a broader level than specific clinical (health) or other outcomes following specific interventions/services.

Indicator The means of measurement to demonstrate change towards a specified outcome– how we decide whether specific outcomes and impact has been achieved. Indicators can be quantitative or qualitative.

Governance A system to ensure that service providers can be accountable for the standards of their services. A clinical governance system is one which enables service providers to continuously improve the quality of their services and protect the best interests of their clients.

Monitoring Ongoing measurement of activity conducted by a service or organisation

Outcome Changes systematically measured against targets for change in client health or welfare or project/service performance

Output Activities, products, services or facilities that a project/service delivers or provides to service users

Quality A framework of agreed standards for rehabilitation services

Quality measurement The ongoing monitoring and evaluation activities and methods used to support an organisational process of continuous analysis, reflection, learning and improvement to ensure quality standards of rehabilitation services for torture survivors, their families and communities.

Service model The way in which the organisation's overall approach, philosophy, key aims and goals and local context, which form the basis of the design of a service, are operationalised. A service model details what will be offered, to whom, how and why.

S.M.A.R.T Specific, Measurable, Attainable, Relevant, Time-bound

Appendices

Resources for monitoring and evaluation of rehabilitation services for torture survivors

Appendix 1: Sample minimum data set
Minimum data set with information required by rehabilitation services can include:
(a) information to conduct initial assessment
(b) information to monitor services offered, services used
(c) information to monitor progress
(d) information to monitor discharge/end of rehabilitation

Referral information
- Referred by…and date referred
- Reason for referral
- Name of assessor/keyworker/responsible staff member
- Date first seen and assessed by rehabilitation service
- Assessor ID

Demographics
- Client's service unique identification number
- Client name, date of birth, gender/sex, address
- Country of origin
- Ethnicity, religious background, first language
- Nationality
- Legal status (citizen, refugee, asylum seeker, IDP, unknown)
- Relationship status (married/civil partnership, widowed, divorced, separated, living together, unknown)
- Education level (primary, lower secondary education, upper secondary education, post-secondary, non-tertiary education, tertiary/higher education (e.g. university)
- Occupation
- Current employment status (unemployed, part-time, full- time, unknown).
- If unemployed, reasons
- Type of housing/accommodation
- Housing condition (poor, moderate, good, excellent)
- Number of people living in the house
- Number of minors living in the same house
- Family and circumstances (who, how many, where, relationships, legal status?)
- External agencies/professionals (e.g. school, legal representative, family doctor)

Needs
- Health problems (physical/medical, psychological)
- Family/relationship problems
- Social welfare problems (e.g. food, adequate housing/shelter, clothing)
- Legal problems, legal situation (e.g. seeking reparation, asylum)
- Risk assessment (risk of self-harm, self-neglect, violence to others, risk from others, child protection concerns, domestic violence, other protection concerns for minors)
- Social functioning

Torture

- WHO was the perpetrator? (e.g. a State official, non-State actor)
- Nature of torture/ill-treatment? Is what the perpetrator did is considered as torture or CIDT according to UNCAT?
- WHAT happened? Nature of torture/ill-treatment? (e.g. using Istanbul Protocol guidance)
- WHERE did the torture happen? (on the street, in place of detention, prison, unknown)
- WHEN did the torture happen? (date(s):...., or unknown)
- Reason for torture related to discrimination? (yes, no, unknown)
- Was person detained in country of asylum (e.g.as asylum seeker)? Where, how long, what happened?

Rehabilitation treatment/care

- Date first treatment/care session
- Nature of services/therapies/activities offered to client
- Nature of services/therapies/activities taken up by client
- Number of attendances and missed sessions
- Length of treatment/care within one service or team more than one team/professional/ intervention involved in client's care

Discharge/ending

- Date of first contact (assessment) with client
- Date of last contact (if treatment/care ending was unplanned e.g. client dropped out, deported, detained)
- Date of end of treatment/rehabilitation (last session)
- Progress (e.g. compared to needs identified at assessment)
- Ongoing needs: health, social, family, welfare, legal
- Risk assessment
- Clinical outcomes (where measures are used)
- Reason for ending: planned, unplanned (e.g. if client disengages from service, client is deported or detained)

Appendix 2: Sample monitoring tools

Monitoring tools can be any method which seeks to capture the minimum data set required by the organisation, in such a way that it can be used easily by practitioners, and it is easy to record (on paper/enter data directly on computer for database entry). The commonest forms most organisations use to capture data are assessment and discharge forms (see below for sample forms). Additional forms for different purposes may also be developed to suit the organisation.

Sample Initial Intake Assessment Form

Name of assessor: _____   Client ID: _____

Name of interpreter (where relevant): _____   Date: _____

Client: Adult ☐ Family ☐ Couple ☐ Minor Accompanied ☐ Minor Unaccompanied ☐

PERSONAL DETAILS

Family name: _____   Title: _____

First names: Sex: _____   Male ☐ Female ☐

Date of birth: _____

Place of birth: **Last permanent residence:**

Country: Country:

Region: Region:

Town: Town:

Nationality: **Ethnic origin:** not asked   **Religion:** none
                                     declined to say   declined to say

_____   _____   _____
                        (if mixed ethnic origin, please specify)

Need for interpreter: ☐ Yes, Language(s) and name   ☐ No

☐ Bilingual practitioner in language:

Current address:	**Legal representative (if relevant):** Name, Address, Contact details
Family doctor: Name, Address, Contact details	
Other contact persons: (relative/friend/school/work) **External agencies involved:**	

FOR UNACCOMPANIED CHILDREN AND ADOLESCENTS:

Carer (name, relationship, address):	**Social Worker/ Significant professional** (name, address):
Telephone number:	Telephone number:

Current civil status:

Single ☐ Married/ with partner ☐ * Separated/ divorced ☐ Single parent ☐ *

Missing partner ☐ * Widowed ☐ Not stated ☐

*Please give details in appropriate table below

Details of family members in household * (tick) OR   NONE ☐

Name	Relationship to client	Date of birth	Legal Status	if in house-hold	if existing client	Whereabouts

*(continue on separate sheet if necessary)

Usual/former occupation: _____

OR tick: Student ☐ Never worked ☐ Not applicable/ Minor ☐ Other ☐

Any stated political affiliation: (Name in full if possible, not just initials)

SITUATION IN COUNTRY OF ASYLUM

Date of leaving country of origin: _____ Via (country): _____

Date of arrival in [country]: _____ Date of asylum application: _____

Detained in [host country]? YES ☐ NO ☐ Client a minor at time of detention   YES ☐ NO ☐

If detained, where: _____ Detention dates: _____

Legal status: _____

Housing: (give options for where, by which authority, conditions – as relevant to the country context)

_____

Welfare / Support: (give options for by whom (family/community/which authority) as relevant to the country context)

_____

Source of referral: (Who referred the client to your organisation: give options relevant to country/local context)

_____

Background

1. **Client or family's story/ reason for leaving country of origin**
   What happened to you?

2. **Details of detentions in country of origin**

- How many times?
- When (dates)?
- Where arrested?
- Why (reasons and charges)?
- By whom arrested?
- Released how/ why?

- Facilities where client detained (e.g. prison, police station, government military camp, rebel military camp)?
- For how long?
- Which groups inflicted the torture/ ill treatment (e.g. uniformed police, government military, rebel military fractions)?

Please continue on separate sheet if necessary

Description of ill-treatment – Provide details (narrative description):

Description of ill-treatment

Important: The following is to help practitioners to record the client's experience which arise from discussing the client's background and noted in earlier pages, but it is NOT to be used in any way as a checklist during the intake assessment itself. Use additional sheets for notes.

Does the client report torture: YES ☐ NO ☐ NOT KNOWN ☐

Does the client report cruel, inhuman or degrading treatment or punishment? YES ☐ NO ☐ NOT KNOWN ☐

	Yes / No	If minor at what age
Detention or imprisonment	Y / N	
Suspended/ hanging	Y / N	
Suffocated	Y / N	
Submerged/ immersed	Y / N	
Kept naked	Y / N	
Sexual assault	Y / N	
Rape	Y / N	
Burnt (acid, heat)	Y / N	
Cut	Y / N	
Electric shock	Y / N	
Toe/fingernails	Y / N	
Beaten/kicked/punched	Y / N	
Falaka	Y / N	
Whipping/beating with implement	Y / N	
Binding, tying, handcuffs	Y / N	
Lost consciousness	Y / N	
Enforced standing	Y / N	
Cold water, hosing	Y / N	
Medical (drugs, dental)	Y / N	
Solitary confinement / isolation	Y / N	
Sensory deprivation (blindfolding, hooding, etc)	Y / N	
Deprivation of fluid (incl. foul water)	Y / N	
Deprivation of food (incl. foul food)	Y / N	
Deprivation of sleep	Y / N	
Denial of toilet	Y / N	
Loud noises/music	Y / N	
Mock execution	Y / N	
Threats of violence/ death to other	Y / N	
Threat of violence/ death to self	Y / N	
Observed violence	Y / N	
Sight/ sound of others being tortured	Y / N	
Detention or imprisonment of family member(s)	Y / N	
Violence to family members (of any kind)	Y / N	
Violent death of family members	Y / N	
Being forced to kill/hurt family members (e.g. child soldier)	Y / N	
Violence against their community	Y / N	
Other (specify):	Y / N	

Intake Worker Health Assessment
Important: for families, parents/guardians may need to report for their children

- What physical problems do you have now?

- When did they start?

- Do you attribute them to any ill-treatment?

- Are you on any medication?

- Have you discussed them with your doctor? If not, you are advised to do so.

Physician Medical Assessment

Name of physician:

Date of assessment:

Signature:

Physical/Medical problems reported by client? ☐ **YES** ☐ **NO**

Current health problems	if yes	if problem present before torture?	Details of problem/ help sought or received:
Respiratory system (e.g. breathing problems, cough)			
Cardiovascular system (e.g. problems related to heart and blood vessels)			
Digestive system (e.g. stomach or bowel problems, anal pain or bleeding)			
Urinary system (e.g. bladder or kidney problems)			
Gynaecology and obstetrics (e.g. irregular bleeding, pelvic pain, vaginal discharge)			
Male genital (e.g. testicular pain / damage)			
Sexually transmitted disease			
Hormone (e.g. thyroid, diabetes)			
Musculo-skeletal system (e.g. stiffness/weakness of the bones, muscles and joints, incl. back)			
Scars (e.g. wounds, bullet injuries)			
Eyes			
Ear, nose, throat			
Skin			
Neurological (e.g. headache, epilepsy, nerve damage/muscle weakness)			
Pain (please specify where and how severe)			
Disability (if yes, is client registered disabled)			
Other (please specify) (e.g. dental)			

Initial Psychological Assessment

Name of health professional:

Date of assessment:

Signature:

General notes: Important: Please use list below as prompts and not as a checklist. For any reported difficulty, try to assess severity and effects on the client's life and functioning. Make notes below or on separate sheet as necessary:

Psychological/ emotional difficulties reported by client? ☐ **YES** ☐ **NO**

Nature of difficulty	if yes	Further information/ examples	Severity of Problem 1-5
Emotional difficulties (e.g., guilt, anger, depressive feelings, loneliness, fear, grief, numbing, dissociation, avoidance) **Cognitive difficulties** (e.g., recurrent intrusive images/ thoughts, poor memory, poor concentration, learning difficulties, memory problems) **Sleeping difficulties** (e.g., insomnia, early morning wakening, nightmares) **Behavioural difficulties** (e.g., obsessive behaviours, substance or alcohol abuse, aggression/violence, avoidance) **Interpersonal difficulties** (e.g., withdrawal, difficulty relating to others, marital / relationship difficulties, difficulties with peers/adults/authority figures for minors) **Social functioning** (e.g. in daily life, school, work at home) **Other psychological difficulties**			
Has the client reported these problems/difficulties to:	if yes	Further information: Which organisation/agency? When received help?	

INITIAL SOCIAL ASSESSMENT

General notes on current social situation and support:

- How are they coping/ personal resources (in school / at home / in the community)?
- What are their social resources/ social support (e.g. are they isolated, friends, church etc.)?

Assessment of social support in UK (please tick as many as appropriate)

☐ No social support ☐ Family ☐ Friends ☐ Work colleagues ☐ School/college friends

☐ Religious links ☐ Political affiliation ☐ Community links

☐ Other _____

Summary of key current issues and priorities of client:
- Include client's/family's own words: their views, wishes, expectations?
- Include any discussion with client /family regarding service options

---

Please indicate priority level as discussed with client:

Current needs prioritised	Priority H = high M = medium L = low
Psychological needs	
Social needs	
Medical / physical needs (e.g. examination, treatment)	
Child/ family issues	
Legal help (e.g. medico-legal report)	
Housing advice/ welfare advice	
Educational needs	
Other (specify)	

Action taken:

1.

2.

3.

Recommendations of assessor:

1.

2.

3.

If you referring the client onwards, what for and why?

Priority of referral: ☐ **Low** ☐ **Medium** ☐ **High**

☐ Individual psychological therapy/support ☐ Group therapy/activities/support

☐ Medical assessment/treatment ☐ Couple or family therapy/support ☐ Psychiatry

☐ Physiotherapy/Complementary therapy ☐ Other/special projects (please specify)

☐ **Referral to external agency (specify below: give options relevant to local/country context)**

☐ **No further action (specify reason below: give options relevant to local/country context)**

☐ Not a priority (e.g. coping well)

☐ Not ever detained or tortured

☐ Receiving help from external agency

☐ Client resettled/re-located/dispersed

Initial Clinical Care Plan

Client

Date:

Keyworker:

Signature:

Main difficulties identified (tick if appropriate)	Priority **H** = high **M** = medium **L** = low	Action Planned	By whom? By when?	Difficulties not within service remit (please tick)	Other internal staff involved? (if yes, specify)	Other external agency involved? (if yes, specify)
Psychological						
Social						
Medical/Physical						
Child/Family issues						
Legal/Asylum						
Housing/Welfare						
Educational/ vocational						
Other						

Risk Assessment made: ☐ Yes ☐ No

Reason why: _____

	If yes, please specify	Action planned: what/ by whom/ by when	Date of next review
Risk of self-harm ☐ YES ☐ NO			
Vulnerability/self neglect ☐ YES ☐ NO			
Violence to others ☐ YES ☐ NO			
Risk from others ☐ YES ☐ NO			
Child protection issues ☐ YES ☐ NO			

Sample discharge form

Name of client: Client ID:

Name of health professional:

Service/team:

Date:

Date of decision to accept client:

Key worker allocated to:

Date of initial assessment:

Other professionals involved in rehabilitation

Other agencies (NGO, State health or social care services etc.):

Brief details of difficulties/history at time of initial assessment:

Brief details of rehabilitation (therapeutic work/interventions/activities):

Summary of rehabilitation services:

Total no. of appointments attended: _____

Total no. of appointments DNA'd: _____

Total no. of appointments cancelled: _____

Progress / Outcome of work

(Tick and give brief details, continue on separate sheet if necessary; use alongside outcome tools where appropriate):

☐ Physical / Medical

☐ Psychological

☐ Social

☐ Family functioning

☐ Legal

☐ Housing

☐ Welfare

☐ Educational/vocational needs

☐ Other

☐ None

Nature of ending

☐ **Planned closure (agreed with client/family)**   ☐ **Planned closure (without agreement)**

☐ **Unplanned closure**

Reason: ☐ Client DNA'd ☐ Client removed ☐ Client detained ☐ Client dispersed ☐ Voluntary return ☐
☐ Status secured/resettled ☐ Client destitute ☐ Illness ☐ Deceased ☐ Other

Is this client currently still receiving rehabilitation from anyone/service internally?

☐ YES   Provide details   ☐ NO

Is this client currently still receiving rehabilitation from anyone/service externally?

☐ YES   Provide details   ☐ NO

Referral made to other service/agency?

☐ YES   Provide details   ☐ NO

Signature of health professional:

Date of final session:

Appendix 3: Audit monitoring tools - templates for use with audit projects

These tools should be used alongside Section 6 of these guidelines. The tools include:

Tool 1: A template summarizing how specific standards which are to be monitored; and the relevant questions to use in the audit project

Tool 2: A data collection form where data collected for the audit purposes is entered

Tool 3: A data collection summary template

Tool 4: An audit project report template

Tool 5: An action plan template

Tool 1: Standards for assessments of all new clients torture survivors

The example provided here is an audit project to monitor assessments conducted with torture survivors who are new clients. Tool 1 provides sample standards that an organisation may specify, and uses them to construct an audit project to assess how well the organisation is meeting those standards. The template can be amended as suitable for the relevant audit project and organisation.

Audit standard which is assessed	Overall quality standard	Questions in monitoring (data collection) sheet
All torture survivors approaching the organisation or referred to the organisation must be assessed on following areas of possible need: -Psychological, physical, medical, social relationships, functioning, family, housing, economic, legal -their strengths, resources -history of torture -legal status	Appropriateness	List the questions which are created to include in the data collection sheet. These will be questions which were applied to the sample of cases reviewed in the audit project (e.g. 50 new clients who were given an assessment in a 12 month period) Questions 1-3 (for example) in the data collection tool monitor practices against this standard
All torture survivors assessed should also have a risk assessment to assess the risk of: -suicide -harm to self -harm to others (including family members and children)	Appropriateness Safety	
All torture survivors undergoing assessment should have a care plan that: • Is tailored to their needs • provides profile of their needs and resources • identified steps to manage the risk of suicide, harm to self or others, including all urgent actions required • indicates which additional and specialist assessments need to be conducted, by whom, and urgency • seeks the views of the client on what they wish and need	Appropriateness Timeliness Safety Acceptability	
All assessment on the full range of needs, resources, torture experiences and other minimum data (as agreed by the organization) is recorded in the X assessment form	Appropriateness	

Tool 2: A data collection form template

This data collection template could be used as a way to record the data collection sheet for each case which is reviewed as part of the monitoring exercise.

Audit ID:	Sex (M, F, Other):	Age (In years):	Language:
	Nationality (and ethnicity if applicable):	Legal status:	Need for interpreter:

No. Question	Yes	No	Notes
1. During the assessment were the following areas of need and strengths assessed?			
2. Psychological			
3. Medical			
4. Physical			
5. Social functioning			
6. Family			
7. Social relationships			
8. Housing			
9. Economic			
10. Legal			
11. History of torture			
12. Legal status			
13. Was a risk assessment completed identifying: Risks to self			
14. Risks to others			
15. Risks needing further assessment (e.g. child protection concerns, domestic violence risks)?			
16. Was assessment of family members and significant others conducted where this risk was identified?			
17. Has all minimum information required for the assessment documented in the appropriate form [according to the organisation's requirements]			
18. Were family members at risk offered information about services available outside or within the organisation?			
19. Has a care plan been completed to include: a profile of the client's needs?			
20. risk to self and others?			
21. any further specialist assessment needed?			

Tool 3: Data collection summary sheet template

This template can be used to enter whether the relevant information was assessed and recorded according to the organisation's standard, as it relates to the audit project in question.

Audit ID number for cases reviewed	Age	Sex	Was the multidisciplinary assessment completed? Yes, No, Non-applicable, incomplete and assessment still ongoing, incomplete	List the needs identified: Psychological Physical Medical Functioning Family Social/ relationships Housing Economic Legal	Was the risk assessment completed? Yes, No, NA, incomplete and ongoing, incomplete and finished	Was risk identified? Yes and action required, No, N/A, Incomplete Information and no further action, incomplete information and action must be taken	Has action been taken to manage risk? Yes, No, N/A, ongoing high priority, ongoing low priority	Is there a completed care plan for the client? Yes, No, N/A, risk identified, further assessment required
1.								
2.								
3.								
4.								
5.								
6.								

Tool 4: A clinical audit report template

The following tool provides a template to report on an audit project, using the example of the project to monitor if comprehensive multidisciplinary assessments have been conducted.

Project title
Audit project: Comprehensive multidisciplinary assessments with torture survivors

Aim
All clients who are referred to [the organization] should be offered a comprehensive, multidisciplinary assessment in accordance with the agreed assessment data required by [the organization]; and recorded in accordance with the standards of [the organization].

Relevant quality standards
Safety
Appropriateness
Timeliness

Audit standards
For example:
1. All torture survivors approaching the organisation or referred to the organisation must be assessed on following areas of possible need:
-Psychological, physical, medical, social relationships, functioning, family, housing, economic, legal
-their strengths, resources
-history of torture
-legal status
2. All torture survivors assessed should also have a risk assessment to assess the risk of:
-suicide
-harm to self
-harm to others (including family members and children)
Etc.

Sample
The audit sample includes all clients who were referred to/self-referred and assessed by [the organization] and accepted for an assessment, during the period of January 2014 and December 2014.

AUDIT STANDARD	Audit results	
1. All torture survivors approaching the organisation or referred to the organisation must be assessed on following areas of possible need: -Psychological, physical, medical, social relationships, functioning, family, housing, economic, legal -their strengths, resources -history of torture -legal status	%	0/0
2. All torture survivors assessed should also have a risk assessment to assess the risk of: -suicide -harm to self -harm to others (including family members and children)	%	0/0

Tool 5: Audit project action plan template

This tool can be used to identify actions following discussion of the results of the audit project. The tool can also be used to monitor the implementation of the actions discussed and agreed by the organisation.

Action plan lead person:	Name:	Position:	Contact details:

Title of Audit Project

Date of audit report:

Date of action plan:

Review date:

Recommendation	Action required (Specify "None" if none required)	Deadline for action (date)	Person responsible	Progress (provide examples of actions in progress, changes in practices, etc.)	What has changed? (not yet actioned, action in progress, action completed, never actioned) Reasons?
1.					
2.					
3.					
4.					
5.					
6.					

Appendix 4: Template for information sheet for adult participants involved in service evaluation research projects[87]

Participating in the evaluation research project
Thank you for your interest in this service evaluation research. The purpose of this letter is to provide you with the information that you need to consider, in deciding whether to participate in the project. The project is being conducted by [name of organisation]. It is funded by the [name of organisation]. The researchers are [name of professional group / discipline].
Please note that taking part in this project will in no way impact on the services you are provided by [name of organisation/centre] or your asylum application with the [Border authorities].

Project Title:
• Provide information which accurately describes the project but in language which is clear, accessible (jargon-free) and appropriate for clients

Why are we doing this project?
• Explain briefly the reasons for this project.

What will you be required to do?
• Explain what would happen if the participant decided to take part.
• Who will meet with them?
• How long will it take?
• What will they be asked to do? What will they not be asked to do?

How might this project impact on you?
• Name the potential harm that that may be experienced.
• Name that they can stop participating and withdraw from the project at any time and that information about support will be provided or referral made to the appropriate clinicians/ keyworker/another appropriate person if necessary to ensure they have support
• State that in the case of disclosure of the risk of harm to themselves or to others the researchers have a duty of care that outweighs the participant's wishes.

Where will the meetings take place?
• Explain how the research meetings / interviews / contact will take place.

Will what I say be confidential?
• Emphasise that the information will remain confidential unless information is disclosed regarding the risk of harm to the participant or others.
• What will happen to the information collected?
• Will it be anonymised? How?
• Who will have access to it?
• Where will it be secured/stored? How will it be protected .i.e. will there be a password?
• State how long all anonymised data will be kept securely (usually for 5 years, but this depends on country context and any existing relevant legislation). After this date all data and the consent form will be destroyed.

Will there be any payment?
• Clarify whether you will be paying participants for taking part?
• Will you pay for travel expenses or lunch?

Can I say no?
- Emphasise that participation in this study is voluntary
- Emphasise that participants are not obliged to take part in the project and that they should not feel in any way forced to do so.
- Remind them that they are free to withdraw from the project at any time.
- Remind them that should they choose to withdraw from the project they will not be obliged to give a reason, nor will there be any negative consequences for them and if they withdraw from the project this will not affect any services they are receiving.
- If they choose to participate, or not, in the project, either way, this will not affect any services they are receiving.

How will the findings form this project be used?
- State what will happen to the outcomes of the project.
- State how the findings form the project will be used, by whom?
- Will it be written in a report, a journal article or other publications?
- Re-state that, as above, anything participants say as part of this project will remain confidential, and no identifying personal details will be included within any publication.
- If the project is presented at a conference the same confidentiality will apply.

Does this project have ethical approval?
- If the project has ethical approval, state that 'this project has been given ethical approval by the [name committee and academic institution]'.
- State: 'if you have any questions or concerns about how the project has been conducted, please contact [provide details of the ethics approval body, contact email address/telephone number].

Who has reviewed the study?
- Inform clients/potential participants that all evaluation projects, including research is reviewed by an independent group of people, to protect your interests and safety.
  Inform clients/participants that the project has been reviewed and given approved by the [name of committee/institution who grants ethical approval].

Any other questions?
- Invite the clients/potential participants to ask any questions and provide contact details if they think of questions later.

Consent form
- Ensure clients /potential participants are asked to provide consent (see template for consent form in appendix 11)

Thank you,

Name of Project lead
Contact details for Project Lead

Appendix 5: Consent form for Adult Participants of Service Evaluation Projects[88]

Project Title:

I understand that this evaluation project/research is being conducted by [name of organisation/ centre].

I have the read/ had someone explain to me verbally only [with an interpreter] the information sheet which describes this project and I have been given a copy to keep.

The nature and purposes of the project has been explained to me, and I have had the opportunity to discuss the details and ask questions about this information.

I understand what is being proposed and what I will be asked to do and what I will not be asked to do.

I understand that my involvement in this project, and the information I give in this project, will remain strictly confidential. Only the researcher(s) involved in the project will have access to any information which identifies me, such as my name and contact details.

I understand that information I provide will be kept confidential unless I disclose information regarding risk of harm to myself or others, in which case I will be informed of the action that would be necessary in order to ensure my safety and that of others

I understand that all information I provide will be anonymised and kept securely for access only by [name who has access to what information: researchers, their supervisors]

It has been explained to me what will happen to the information I provide once the project has been completed.

I understand that the findings form the project will be shared with others [published in a report, journal article, reports for the centre/organisation etc.] but no details which identify me or place me at risk of harm will be shared with others

I understand that my participation in this project is voluntary.

I freely consent to participate in the project which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the project at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS) _____

Participant's Signature _____

Date: _____

Project lead person's Name (BLOCK CAPITALS) _____

Project lead person's Signature _____

Date: _____

Name of interpreter (where used): _____

Signature of interpreter: _____

Date: _____

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