Guidance Note

Studies and research at Handicap International: Promoting ethical data management

Operations and Technical Resources Division
September 2015

GN | 04

Contents

Foreword: About this guidance note...

1. Why this guidance note on ethics?

An increasing number of studies and research projects are carried out on Handicap International's programmes. Indeed, the production and use of reliable data are now crucial to all stakeholders in humanitarian aid and development. Within Handicap International, this kind of data is needed to guide and adapt our interventions and improve our practices; on the outside, institutional donors are now asking for evidence of the outcomes and impact of the actions they finance and the national or international authorities targeted by our advocacy actions are seeking solid information to help move their policies and legislation forward. The data management process must therefore generate good-quality information, while respecting all the individuals involved in the preparation, collection, processing, analysis and sharing of this information, whether they are affiliated to Handicap International, partners or subjects of a study or research.

2. What does this guidance note set out to do?

This guidance note draws on Handicap International's field experience, but also on reference documents and scientific articles on the ethical issues surrounding the production and analysis of reliable and conclusive data, otherwise known as "evidence", in humanitarian aid and development settings.

It aims to raise the awareness of Handicap International's operational and technical staff and their partners to the ethical questions to be considered when managing data (preparation, collection, processing, analysis and sharing of information). It reaffirms the ethical principles underpinning the organisation's actions and transposes them into operational guidance in the form of eight ethical recommendations applicable to studies and/or research[1] in our intervention settings.

---

[1] **Study [survey]:** Generic term covering the activity of collecting, analysing, disseminating and using evidence with a view to providing further objective information on a population, a situation, a context or a practice. Studies do not seek to create new knowledge by means of innovative approaches or methodologies. At Handicap International, studies [and surveys] are technical in nature, but can take various forms (Knowledge Attitudes and Practices surveys, service user satisfaction surveys, etc.). They have two main objectives: to obtain information on a situation and obtain a clearer understanding of a context (initial situation and needs assessment) or to show the outcomes/ impacts of an intervention with beneficiaries (monitoring & evaluation).
Research: Activity aimed at collecting, analysing, disseminating and using new scientific knowledge obtained using stringent, reliable and reproducible methodologies. The notions of novelty, creation and innovation are essential here. Handicap International conducts applied research, which means that the findings are used and transposed into concrete actions. Applied research can be broken down into three categories, according to its end purpose: action

These recommendations are not intended as directives or rigid and restrictive action standards, provided their non-respect does not conflict with other obligations[2]. They should be considered more as markers for guiding action.

3. Who is it for?

This guidance note will be broadly distributed. It is intended for all our programme divisions staff (project managers, technical and/or operational coordinators, programme directors, project officers and desk officers), our technical resource staff, their partners and any consultants working for Handicap international.

4. What does it cover?

Data is collected, analysed and shared in a wide range of situations within the organisation. In fact, this type of activity is both cross-cutting (as it concerns all the operational divisions and all the technical sectors) and multi-purpose (as serves a variety of objectives: improving our knowledge of a context, increasing the relevancy of the approaches used in our interventions, evaluating the outcomes and impact of Handicap International's action, etc.). The question, therefore, is when to use this guidance note.

- **With regard to activities:** The recommendations made here should be taken into consideration in all research carried out at Handicap International, whether quantitative or qualitative, and for certain technical surveys. However, as these recommendations are a practical translation of ethical principles already underpinning the organisation's mandate, they can also be useful and profitable when implementing other activities.

- **With regard to sectors:** These recommendations should be taken into account in all sectors, but differently, depending on the sensitivity of the issue and the type of material collected (personal and/or "sensitive" data – see "About data" – or biological material, such as blood tests). Many sectors are concerned, including health (e.g. HIV, sexual and reproductive health, mental health), protection and gender-based violence.

---

research, operational research and advocacy research. Research at Handicap International is a multi-actor process involving programme experts (Programme Divisions - field and head office), technical experts (Technical Resources Division) and research experts (Knowledge Management Unit or external academics).

[2] Such as the application of the Project Quality Framework, for example

- **With regard to intervention settings:** All our intervention settings are potentially concerned. The number of guides and other reports produced for humanitarian operators is a clear indication that, in interventions and studies carried out in emergency contexts, ethical matters have become a subject worthy of serious reflection[3].

- **With regards to the use of information:** The recommendations proposed here should be followed when the information generated will be used in advocacy activities, to objectively improve practices or to plan or programme new activities. Indeed, in all these cases, data needs to be of good quality, reliable, valid and obtained using a process that respects not only methods, but individuals and their rights.

5. How will it updated?

To make sure this guidance note remains pertinent, it will revised on a regular basis. Suggestions or further lessons learned from field experience will be included in future versions.

Please send any comments to:

Aude Brus, Technical studies and scientific research coordinator

Email: abrus@handicap-international.org

---

[3] Some examples:

- Curry D, Waldman RJ, Caplan AL. 2014. An Ethical Framework for the development and review of health research proposals involving humanitarian contexts. Department for International Development (DFID) & the Wellcome Trust.
  http://www.elrha.org/r2hc/publications/research/ethics-review/ethics-review/
- Dromer C, Desmarest A, Delorme A. 2010. For ethics in the field: sensitive personal data management (Health – Life stories). Médecins du Monde.
  http://www.medecinsdumonde.org/Publications/Guides-a-l-usage-des-professionnels-de-l-humanitaire/Pour-une-ethique-de-terrain-Gestion-des-donnees-personnelles-sensibles
- Ford N, Mills EJ, Zachariah R, Upshur R. 2009. Ethics of conducting research in conflict settings, In Conflict and Health, 3:7.
  http://www.conflictandhealth.com/content/pdf/1752-1505-3-7.pdf
- Allden K, Jones L, Weissbecker I, Wessels M, Bolton P, Betancourt, TS, Hijazi Z, Galapatti, A, Yamout R, Patel P, Sumathipala A. 2009. Mental health and social support in crisis and conflict: report of the Mental Health Working Group, In Prehospital and disaster medicine, 24 (suppl.2).
  http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.176.1491&rep=rep1&type=pdf

Concerning data...

The data management process is shown in figure 1. It includes the following stages: 1) preparing the process; 2) collecting data; 3) processing data; 4) analysing and interpreting data; 5) sharing and using the information generated.

During this process, the **data,** i.e. the unrefined and non-interpreted material collected, is first transformed into **information,** i.e. processed, analysed and contextualised data, then into **knowledge,** i.e. information used and exploited in concrete situations that will help with decision-making.

The various stages will be referred to regularly in this document as the recommendations to be considered for ethical data management are developed.

Plan
Data is selected and adequate resources (time, budget, skills) made available.

Collect
Data is collected, using a qualitative, quantitative or mixed method.

Process
Collected data is entered into a database when quantitative or transcribed when qualitative.

Analyse and interpret
Collected and processed data is analysed and interpreted according to the objective and context.

Share and use
Generated information is shared (publications, workshops, conferences, etc.) to help bring about a change.
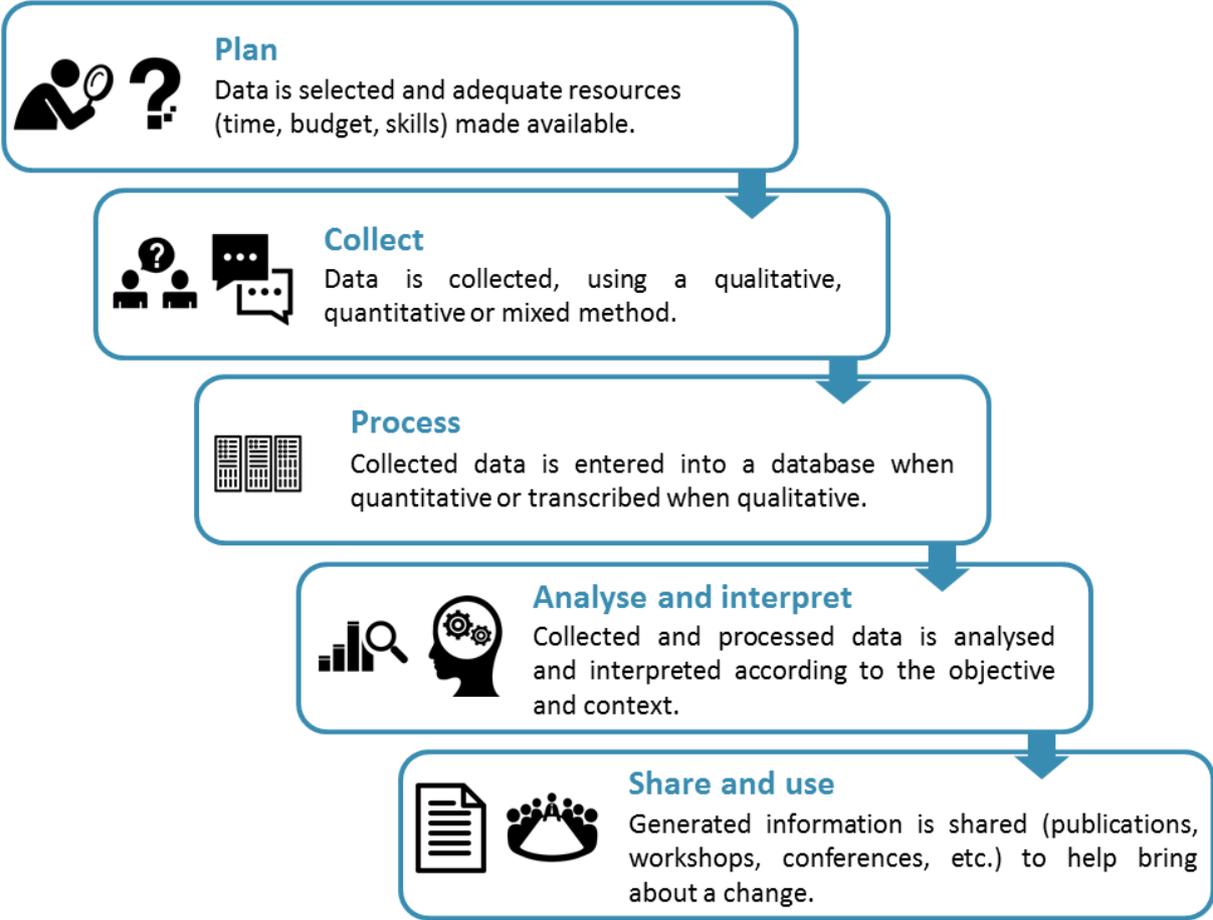
Figure 1 - Stages in data management

>•< Types of data

To guarantee an ethical approach, the management of personal and/or sensitive data requires specific mechanisms to be put in place.

"Personal" data refers to any information concerning an identified individual or an individual who can be directly or indirectly identified by reference to an identification number or to one or several elements specific to him or her[4].
→ This data is made up of elements that make people immediately identifiable (full name, GPS location, address, etc.) or identifiable when combined: profession, date of birth, name of village, state of health or physical, intellectual or psychological characteristics (especially related to an impairment: amputation, scar, a specific pathology, etc.).

"Sensitive" data refers to any information concerning racial or ethnic origin, public opinions, philosophical convictions or religious beliefs, trade union membership, physical and mental health [or state of health] and sex life[5].

NB:
Data is not limited to digital or text forms. It can also be in the form of pictures, videos or any other information-providing media and requires equal vigilance and as many precautions to be taken.

---

[4] Article 2 of the French Act n° 78-17 of 6 January 1978 on Data Processing, Files and Individual Liberties, amended by Act n°2004-801 of 6 August 2004.
[5] Article 6 of Convention 108 of the Council of Europe and Article 8 of Directive 95/46/EC of the European Parliament and Council, of 24 October 1995, for the protection of individuals with regard to automatic processing of personal data.

Ethics: from theory to action

1. Theoretical ethics

Ethics can be defined as a form of critical reflection guiding actions and addressing the question of the right conduct to adopt in a given socio-cultural context. They have no prescriptive or normative value. They are more a guide to acting "justly" intended to safeguard individual and collective interests and ensure respect for individuals and populations. So, ethics are not an end in themselves, but rather a tool for establishing a framework for our actions that is respectful of people and their rights.

There are a variety of ethical models[6]. Although they differ according to the referential used, they become coherent and complementary when theoretical ethics make way for applied ethics. Whatever the field (health, computer technology and cyber sphere, humanitarian aid, etc.), the underlying reflection is based on the common notions of respect, dignity, autonomy and individual liberty, anticipation and consideration of positive and negative effects and protection. These notions may be written into codes of conduct (including obligations and interdictions which, if transgressed, lead to sanctions), codes of deontology or charters, depending on the organisation.

2. Applied ethics

Reflection into the ethical principles to be applied when producing and managing information for research purposes was first launched in the **health sector** - a sector where there is much research involving human subjects, and so much scope for ethical errors. The medical field has indeed given much and repeated consideration to its representations and practices in order to cope with social mutations and successfully engender and manage professional transformations (e.g. in the field of genetics, assisted fertilisation, etc.).

---

[6] There are several approaches to evaluating an action. For example, an action may be evaluated with reference to norms, duties and moral imperatives (deontological ethics developed by Emmanuel Kant, 1724-1804) ; or according to its foreseeable consequences and the balance between good and bad - a balance which must maximise the good consequences (consequentialist ethics developed by Jeremy Bentham, 1748-1832) ; or be considered the result of a balance between oneself (self-esteem), another and "just" institutions, with mutual concern at the centre of the action (ethical aim developed by Paul Ricœur 1913-2005).
See also: CP MERG. 2012. Ethics documentation review: guidelines and codes, in Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature, Statistics and Monitoring Section / Division of Policy and Strategy, UNICEF, New York; pp. 11-18.
http://data.unicef.org/corecode/uploads/document6/uploaded_pdfs/corecode/EPDRCLitReview_193.pdf

Founding texts[7] have thus been developed to protect individuals which establish **three basic principles**[8] for defining what constitutes "ethical research":

- **Respect for persons**
  Two assumptions underpin this first principle: all individuals are autonomous agents, in other words free and capable of deliberation about personal goals and of acting in accordance with these deliberations. The decisions, attitudes or stances of individuals should not be judged. Showing empathy, taking care (i.e. not being negligent or indifferent), listening actively and interacting are means of showing respect for vulnerable individuals.

- **Beneficence**
  This principle focuses on the need to secure the well-being of the subjects or the community involved. Therefore, we should "do no harm" and protect and preserve their physical, mental and social well-being ("protection"). We should also respond to the needs expressed by a population to ensure the relevance of interventions ("participation").

- **Justice**
  The right balance between the benefits and risks of an action must be established between the various actors involved in an action. The idea of equity is essential. The selection of subjects is a key aspect of this principle. The selection process should not discriminate, nor should it be based on convenience (for example, for environmental; visibility, communications or other reasons).

The **humanitarian aid and development** field has also seen many environmental transformations over recent years:
- dynamics combining emergency and development actions are now encouraged;
- the North / South, aid giver / aid receiver polarisation has been challenged by the arrival of new actors from emerging countries[9] ;
- relations between the different actors working in the humanitarian space are changing[10];

---

[7] Health is the sector in which there is the most legislation on ethical issues: Nuremberg code (1947), Declaration of Helsinki (1964 – rév. 1975, 1983, 1989, 1996, 2000, 2008, 2013), Belmont report (1979), Nuffield report(2005)…
[8] Principles: A standard serving as a reference, values on which action or conduct can be founded.
[9] Dato J. 2013. Anthropologie, sciences sociales et aide humanitaire : quels liens ? In Informations et commentaires, 164 : 13-15.
http://www.grotius.fr/anthropologie-sciences-sociales-et-aide-humanitaire-quels-liens/
[10] Audet F. 2011. L'acteur humanitaire en crise existentielle : les défis du nouvel espace humanitaire, In Études internationales, 42 (4) : 447-472.
http://archives.cerium.ca/IMG/pdf/1007550ar.pdf

- the active participation of assisted populations has become an action principle[11], raising questions about how the competencies of aid workers should be developed[12];
- the perceptions of aid and aid workers held by assisted populations are not always positive[13], etc.

These changes, along with an increasingly complex operational environment, call for a critical analysis of the intervention modalities and practices used by actors in humanitarian aid and development, underpinned by ethics applicable to these activities. Indeed, humanitarian aid and development are part of a complex world and not all the situations encountered can be conceptualised. This makes it difficult to develop rules for all occasions: flexible decision-making tools are needed to guide the action. Although aid ethics are based essentially on values of humanity demanding that assistance be provided to all people in distress, they can also be broken down and based on basic underlying principles, such as autonomy, well-being, doing no harm and justice[14].

3. Ethics at Handicap International

The essence of these basic principles is reflected in the five main principles found in Handicap International's Charter: **humanity, solidarity, impartiality and equity, independence and commitment**[15]. Handicap International's action aims to improve people's living conditions and is based on understanding and respecting beliefs, culture and local practices, respecting and supporting traditional solidarity mechanisms, delivering aid adapted to identified needs, doing no harm and eschewing discrimination. There is no political agenda behind our interventions.

These principles underpin all Handicap International's actions and are clearly reflected in our policies and practices:

- The new Project Planning, Monitoring and Evaluation policy for Handicap International's projects incorporates ethics as a specific criterion in its Project

---

[11] Atlani-Duault L, Vidal L, 2009. Anthropologie de l'aide humanitaire et du développement: des pratiques aux savoirs, des savoirs aux pratiques. Armand Colin, 312 p.
[12] Breslin S. 2015. Shooting ourselves in the foot: A look at the humanitarian sector's self-inflicted wounds, 9 p.
http://www.peopleinaid.org/pool/files/pubs/ScottBreslin-Self-inflicted-Dilemmas.pdf
[13] Abu-Sada C. 2010. La perception de MSF sur les terrains d'intervention : le cas du Niger, In Humanitaire, n° 24.
http://humanitaire.revues.org/704
[14] Mattei JF. 2014. L'humanitaire à l'épreuve de l'éthique. Liens qui libèrent (Les), 179 p.
[15] Handicap International. Mission, Scope of activity, Principles of intervention, Charter, Visual identity. Institutional Policy collection.
http://www.hiproweb.org/uploads/tx_hidrtdocs/IPMissionScopeActivityPrinciplesInterventionCharterPrint.pdf

Quality Framework[16]. The organisation's ethical principles are reflected in three essential action commitments: non-discrimination (the project addresses the needs and interests of all individuals in an inclusive and differentiated manner); "do no harm" (an analysis is carried out of the risks of generating short- or long-term negative effects for the communities); respect of values (project teams and partners are aware of their responsibility for complying and ensuring compliance with Handicap International's institutional policies);

- Reflection has been carried out into the ethics surrounding testimony-gathering and staff reminded of the need to respect principles of objectivity, impartiality, independence and confidentiality when collecting and using information[17] ;

- Federal Communication Division has also specified the principles to be followed when using beneficiaries' testimony and photos for fundraising purposes[18] ;

- Lastly, the policy of Protection of Beneficiaries from Sexual Exploitation and Abuse and its tool kit for managers[19] provide preventive measures and mechanisms to put in place for managing proven cases and offers ethical recommendations for handling complaints and investigations (confidentiality, anonymity, protection, professionalism and impartiality).

The ethical principles adopted and implemented by Handicap International concern not only the people who work for the organisations, but also our donors and partners (operational and strategic).

Existing documents provide ethical guidelines for very specific sectors, but there are no recommendations as yet on the ethical production and management of data for use in studies and/or research. This guidance note endeavours to address this gap.

---

[16] Handicap International. 2015. Project Planning, Monitoring and Evaluation Policy. Institutional Policy collection.
http://www.hiproweb.org/uploads/tx_hidrtdocs/IP06_PME.pdf
[17] References:
- Herlemont-Zoritchak N. 2013. Ethique et pratique du témoignage dans les contextes de déplacements forcés : l'exemple de Handicap International, In Récits et paroles de migrants en quête d'asile : quels enjeux, quels effets sur la santé mentale ?, Actes du colloque du 18 octobre 2012, Lyon/Bron : Réseau Samdarra, p. 31-37.
http://www.samdarra.fr/documents/ReseauSamdarra-18octobre2012.pdf
- Herlemont-Zoritchak N, Rave A. 2012. Using testimony: supporting our denunciation and advocacy actions. Internal document.
[18] Fundraising and Communication Division / Handicap International Federation, 2014: Guidelines for fundraising appeals. Internal document
[19] References:
- Handicap International. 2011. Protection of beneficiaries from sexual exploitation and abuse. Institutional Policy collection.
http://www.hiproweb.org/uploads/tx_hidrtdocs/PI03-ProtecBenefic-EN.pdf
- Toolbox for the implementation of Handicap International's policy on protection from sexual exploitation and abuse (PSEA), Internal document, available on Intranet.

Ethics: recommendations

The ethical principles adopted by Handicap International can be transposed into eight recommendations specific to managing data as part of a study or research:

1. Guarantee the security of subjects, partners and teams
2. Ensure a person / community-centred approach
3. Obtain the subjects' free and informed consent
4. Ensure referral mechanisms are in place
5. Ensure the security of personal and sensitive data at all stages of the activity
6. Plan and guarantee the use and sharing of information
7. Ensure the expertise of the teams involved and the scientific validity of the activity
8. Obtain authorisation from the relevant authorities and organise an external review of the proposed study/research.

These recommendations are not exclusive of each other; they are interdependent.

**Figure 2 - Eight recommendations for the ethical management of data
in studies and research at Handicap International**

Recommendation 1 - Guarantee the security of subjects, partners and teams

Information gathering, analysis and sharing activities must not harm or endanger in any way the different actors involved in these activities (subjects, households and communities, but also teams, organisation and partners). This recommendation is consistent with Handicap International's security policy, which makes the safety of field teams, partners and populations a priority[20], and with our principles of intervention, notably point 9.1: "Handicap International exercises its professional responsibilities as an international aid organisation according to the following principles:

- "do no harm", by measuring the consequences of our acts and causing no injury;
- "overlook nothing", by seeking to mobilise all suitable means available"[21].

The notion of risk is central and defined in terms of the potentially harmful short - to long-term consequences of data management on the well-being and security of any of the parties involved. Any risks incurred must be minimal for everyone, and must never outweigh the benefits (favourable harm/benefit ratio). We may therefore decide against collecting and using data if there is any doubt about the risks likely to be incurred by the people involved, even if they have given their prior consent. It would be unacceptable for the production of data to take priority over people's security.

The risks may be of different kinds, depending on the actors concerned. Although not all risks can be identified, some of them can at least be anticipated. Table 1 gives a non-exhaustive list of the potential risks associated with data collection, both for the subjects and for Handicap International's teams. Identifying potential difficulties, recognising risk factors and planning how to manage them are essential aspects of the design and implementation of a study or research. Training is also necessary to make sure that our representatives in the field are themselves conscious of and equipped to deal with these potential risks. If the probability and severity of the risks identified are deemed to be too high, and if no solution is found to ensure a favourable risks/benefits ratio, a study project may be turned down.

Finally, the protection of everybody involved must be an intrinsic consideration in all stages of the data management process. Some aspects of protection are cross-cutting and will be found in other recommendations (recommendations 5 and 6, for example).

---

[20] Handicap International. 2012. Tackling the risk: Handicap International's Safety and Security Policy. Institutional Policy collection.
http://www.hiproweb.org/uploads/tx_hidrtdocs/PIO5-SecurityPoilicy-EN.pdf
[21] Handicap International. Mission, Scope of activity, Principles of intervention, Charter, Visual identity. Institutional Policy collection.
http://www.hiproweb.org/uploads/tx_hidrtdocs/IPMissionScopeActivityPrinciplesInterventionCharterPrint.pdf

Table 1 - List of potential risks in data collection

Types of risk	For the subject	For Handicap International's teams
Physical risks	Risks of reprisals or detention if the subject is identified and/or if the issue is considered sensitive by the national authorities or by other actors (spouse, relatives, neighbours, employer, etc.).	• Risks of accidents, kidnappings or of contagion in situations of epidemics • Risks of reprisals and detention if the subject is considered sensitive by the national authorities or the community
Psychological risks	• Taking part in a survey may generate expectations, or at least the hope of obtaining assistance (humanitarian, financial or other) • Aggressive or ill-adapted interview techniques may make the subject uncomfortable and be perceived as intrusive • Talking about situations or experiences related to sensitive topics may be a source of discomfort or stress, and may even rekindle traumas and generate anxiety or a feeling of humiliation	• Hearing certain accounts and gathering sensitive information, or managing somebody's stress, may cause unease and/or stress • If the population is often approached for data-collection purposes, fatigue may set in and give rise to resentment to aid workers
Social risks	Being interviewed may: • Accentuate the stigmatisation of groups who are already socially vulnerable within the community • Undermine links between an individual and his or her entourage • Create imbalances within the community itself (be a source of jealousy among people not participating, for example) • Or, on the contrary, strengthen pre-existing dynamics or positions	Data collection may arouse feelings of wariness or even lead to losing the trust of the community if there are suspicions about who the information is for and how it will be used (for example, intelligence services in certain countries), which could place the field team in difficulty
Legal risks	Risks of prosecution, depending on the information provided by the subject (e.g. denunciations)	Risk of complaints being filed if the necessary authorisations have not been obtained, or if cultural conventions have been ignored or if consent has not been clearly obtained

Simple measures can be taken to reduce these risks. For example, if they are related to the sensitivity of the issue:

- Find out what is personal or sensitive information in the locality, both in legal terms and with regard to social conventions and cultural norms;

- Identify data that will require specific measures to be taken to guarantee its confidentiality and security and prevent its instrumentalization for political or other purposes;

- Pay careful attention to the methodology used and when creating data collection tools (by working on how questions on sensitive issues are formulated and how these questions follow on from each other);

- Do not force anyone to confide;

- Organise and deliver effective training for data collection agents;

- If necessary, offer subjects psychological support after data collection;

- Debrief the teams regularly after data collection;

- For digital data collection (i.e. by telephone or tablet), make sure all traces of the data are removed from devices after transmission.

Recommendation 2 - Ensure a person or community-centred approach

There are three dimensions to this recommendation:

- Respect for the cultural environment: the target population's traditional values, social practices, beliefs and representations must be taken into account when implementing data collection and analysis activities;

- Respect for individuals' specific characteristics: sex, age, impairments, sexual orientation are all factors to be considered in the approaches developed;

- Added-value for the community and/or the individuals targeted: the activity must be linked to one or several needs identified by the target population and/or the aid actors.

The first two dimensions concern the conduct of the teams in the field and the adaptation of the methods and modalities used in collecting and analysing data[22] (reliable translation of questionnaires, development of visual aids for people with intellectual disabilities, interviews with a third person present for minors or people with disabilities unable to answer questions directly, women data collection agent to interview women, disaggregation of data according to type of disability, etc.). Training also plays a key role, as the field teams are given technical guidance during these sessions.
Ensuring an activity and its aims are adapted to needs, requires sound knowledge of the population concerned and reliable information - obtained using a participatory approach, for instance – on which to build the project (linked to the initial diagnosis, for example).

Participation by the communities targeted is an important cross-cutting aspect of this recommendation. Indeed, gathering the experience and solutions proposed by the people directly concerned in order to adapt methods accordingly and identify priorities together will help ensure the coherency and quality of the exercise.

An approach centred on individuals /the community (but which takes into account the risks outlined in recommendation 1) will:

- facilitate acceptance of the data collection exercise and associated aid;

- optimise the aid process, as it will ensure the objectivity of the needs and the relevance of the response;

---

[22] Practical advice on making interviews accessible to people with different types of disability can be found in the Practical guide ''Using testimony: supporting our denunciation and advocacy actions'', Handicap International, 2012, p. 29-31.

- ensure a balanced relationship between the actors involved: placing the subject at the centre does away with the traditionally asymmetric power relations between interviewer and interviewee and allows a more balanced relationship to develop;

- ensure those who usually remain silent are given an opportunity to express themselves by providing possibilities for broad participation and paying attention to the specific characteristics of groups and individuals. Ensuring that everyone expresses themselves, not just the individuals/groups who are most comfortable with this type of exercise, will make our response more "equitable".

- over the longer term, improve the target population's perception of aid.

>•< **Collecting gender-sensitive data: an anthropological study of WASH in Sindh province, Pakistan - 2012**

In 2012, an anthropological study analysing practices and representations linked to health, water, sanitation and hygiene was carried out in the Sindh province of Pakistan by Humanitarian Action Division. Women were rapidly identified as key players, as it was their responsibility to manage all their household's water requirements, whether for domestic or personal hygiene purposes. The methodology was therefore adapted to enable data researchers to meet with them, while respecting cultural codes. The data researchers included women who were able to run discussion groups with their subjects and take part in their daily activities to observe practices and compare what was said with what was done. Without this gender-sensitive approach, a lot of information would not have been collected or certain observations would not have been correctly analysed and interpreted.

Recommendation 3 - Obtain subjects' free and informed consent

All subjects must receive the same information, understand what is going to be done and give their free and informed consent to participating.

The notion of "consent" implies that the people concerned have actively approved the use of the personal data to be collected. They have been reminded of their rights and given time and space to reflect and, if they wish, to decline the proposal to participate. They need to understand that they are not taking part in the study in their own immediate interest, but as part of an action with a broader objective. The term "informed" implies that people make a choice on the basis of reliable, clear, accessible and therefore understandable information. The term "free" implies that people take their decision without constraint or physical, moral, social, economic or political pressure.

In certain cases, this consent is the final stage in a multi-level process for guaranteeing individuals' free participation. Collective consent may also be required and involve providing information sessions for the local authorities, community or family[23]. However, collective consent does not replace the need for individual consent.

Obtaining free and informed consent depends on a number of factors:

- **Information:** During the initial discussion with the potential subject, data collection agents should introduce themselves and explain the purpose of the data collection (objectives and use of the information); present the potential risks; guarantee the confidentiality of the data collected; remind the person of his or her rights (right to refuse to participate, not to answer certain questions and to stop the interview at any stage); specify that participation is free and give a contact name (if there are questions or if the person wishes to report an abuse of the process or a problem).
  The choice of information and amount of detail to be given can be difficult to define, as it is not always easy to find the right balance between full information meeting ethical imperatives and information overload. The focus should be on transparency and essential information rather than excessive and potentially confusing detail.

- **Understanding the information:** Various factors influence the understanding of the information given: a person's maturity, language level, spoken language, capacities, education level or even their psychological state are all factors that can create interference. It is therefore essential to use a style that is simple,

[23] Strauss RP, Snegupta S, Quinn SC et al. 2001. The role of community advisory boards: Involving communities in the informed consent process, In Am J Public Health, 91: 1938-1943.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446908/

clear, understandable and accessible and to use aids, if this can help with understanding. If the data collection exercise is to include the participation of people with disabilities, the aids should be adapted to their impairments (visual aids for people with intellectual disabilities, material in braille for people with visual impairments, sign-language for people with hearing impairments, etc.).

The data collection agents must take time to share information during the interviews and make sure that the subject has interpreted it correctly. For example, he/she could try asking questions to make sure the person has understood, or ask the person to reformulate what has been said.

- **Format:** Depending on the population concerned and the cultural context, it may seem better to obtain oral rather than written consent. Indeed, written consent is not always appropriate, notably when the subjects are not literate or have a low level of education. Signing a document that they don't understand may make them uncomfortable (feel inferior) or even suspicious (the team may be suspected of collaborating with the authorities). However, it is advisable to obtain written consent whenever possible.

- **Third-party consent:** Individual consent is compulsory, but depending on the situations and the contexts, it may be necessary to go through a third-party (legal guardian, family member, etc.) to obtain it:
  - Either for reasons of social and cultural convention: In certain cultures, the husband's permission, or that of a "male guardian" is required before approaching a woman. Her personal consent remains essential and compulsory, however.
  - Or because of age: To obtain the participation of a child or adolescent, the person in charge of the child must be consulted (direct family, legal representative or other relative). However, the child must be informed, even if a third-party retains the right to agree to or refuse his/her participation. It is therefore recommended to proceed in two stages and at two levels: first with the adult in charge of the child and then with the child him or herself. It is also wise to establish the age at which someone is considered to be an adult. In some contexts, people are considered to be major, and so responsible, from the age of 15 or 16. In this case there is no need to go through a third-party, but it is important to make sure that this information applies to the target population.
  - Or because of a limited capacity to understand due to a disability: this can be true of people with severe intellectual, mental or psycho-social disabilities (in a psychotic phase or suffering from trauma, for example). The person in charge of the individual concerned (direct family, legal representative or other relative) is responsible for giving or refusing authorisation to participate. However, even if the decision is taken by a guardian, it is still important to try and explain to the person concerned and inform him or her about the issues and objectives of the data collection (visual aids, for

example). If the guardian is not present, special arrangements will need to be made to ensure consent.

- **Free and voluntary consent:** The subject must agree to participate in the data collection without any external pressure or constraints. This is essential for ensuring the quality and reliability of the data to be collected. It is, however, difficult to control, as even tacit power relations between the individual and his/her environment (influence of religion or cultural values), between the individual and his/her community (what value should be accorded to individual consent in cultures centred on the community and the family?) or between the individual and the data collection agents (who represents the organisation) can weigh heavily and affect the subject's decision. Subjects should not be offered any financial remuneration or promised aid in return for their participation. They may, however, be compensated (transport costs may be covered or a snack provided, for example), but in no circumstances will they be paid for the information they provide.

Free and informed consent is therefore an essential aspect of ethical data management. It requires the field teams to be correctly trained in the process of obtaining consent and to understand its importance and the issues involved, as they are the ones in direct contact with the subjects and responsible for this aspect.

>•< **Stimulative physical therapy in Mali**

In 2013, a study was carried out in Mali to analyse the outcomes of stimulative physical therapy on the psychomotor and cognitive development of children aged between 6 months and 5 years and suffering from severe acute malnutrition. The children's caretakers were given clear and easy-to-understand information on the objectives and organisation of the study (number of sessions, health professionals involved, duration, etc.) during the initial medical consultation. The confidentiality of the information was guaranteed. They were free to accept, refuse or stop the study at any time. At all times, if they felt the need, caretakers could contact the people responsible for study.

Recommendation 4 - Ensure referral mechanisms are in place

A difficulty may be identified or a complication caused during data collection activities, in which case subjects should be given guidance on how to obtain appropriate accompaniment and/or care[24]. In other words, referrals may become necessary as a direct or indirect consequence of these activities.

The question of referrals is all the more crucial when the issues discussed are sensitive (such as maltreatment or violence[25]), or when the activities are liable to disrupt the relational, emotional or economic equilibrium of a household or community (e.g. involve the announcement of HIV infection or a disability[26]). These aspects must be taken into account to ensure there is still a favourable balance between the benefits and risks of an activity.

It is essential to take all necessary measures, within the limits of available means and resources, to ensure the well-being and protection of the subjects of the study/research. Individuals are of course free to decide whether to follow the advice given and accept the help offered.

Information is the first stage. Teams must be able to rapidly inform people in possible need of assistance about available services and existing referral mechanisms in the intervention area[27]. They should be capable of delivering this information directly, if they have it to hand. Otherwise they should research it and get back to the people concerned as quickly as possible.

---

[24] See recommendation 1 on the potential risks associated with data management, and recommendation 3 on the need to inform people about these risks when seeking consent.

[25] At international level, guides on ethical issues and violence have been produced over recent years, focusing on the need to provide individuals with support. For example :
  - CP MERG. 2012. Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature, Statistics and Monitoring Section / Division of Policy and Strategy, UNICEF, New York.
    http://data.unicef.org/corecode/uploads/document6/uploaded_pdfs/corecode/EPDRCLitReview_193.pdf
  - ICRC. 2013. Professional standards for protection work. International Committee of the Red Cross, Geneva.
    https://www.icrc.org/eng/resources/documents/publication/p0999.htm

[26] On the early identification of disability, see: Gottlieb C and Durkin M, 2011. Identification of Child Disabilities in Low- and Middle-Income Countries, In Inclusive Early Childhood Development – an Underestimated Component within Poverty Reduction, Disability and Development Cooperation, Caritas international/Germany, Kindermissionswerk, "Die Sternsinger" Kindernothilfe (eds.): p. 109-118.
http://www.bezev.de/fileadmin/Neuer_Ordner/Literatur/Bibliothek/Publikationen/Inclusive_Early_Childhood_Development_Tagungsdokumentation.pdf

[27] What should be done if no services are available or if treatment is not possible (no health cover, treatment at the person's expense, etc.)? Reconsider the interest and usefulness of the activity, refer back to the evaluation between the associated advantages and risks, and weigh up the pros and cons as objectively as possible: aid actors must be guided by the higher interest of the individuals concerned.

These people should also be accompanied to the first referral service point to ensure they will be given the care they require. Indeed, the populations targeted are vulnerable and in need of specific support and accompaniment as they are not always individually capable of taking initiatives. Furthermore, services are rarely accessible. This action is particularly important if the objective of the study/research is to identify disability in a child or test for a disease that endangers the well-being of individuals (diabetes or HIV, for example). It is essential to anticipate what might happen after announcing this kind of news and to know where to send these individuals and their families for follow-up and what kind of support they can be given[28].

>•< Disability and HIV research: the "HandiVIH Project"

 In Yaoundé (Cameroon), research was carried out of disabled people's vulnerability to HIV infection with a view to constituting a body of epidemiological and anthropological data on disability and HIV. The main objective of this research was to measure HIV prevalence among people with disabilities. All the subjects of the study were given information and advice on HIV, a diagnostic test and the necessary support prior, during and after the serology test. Furthermore, people diagnosed with an HIV infection were referred to an HIV/AIDS treatment centre and accompanied on their first visit. These centres had received prior training in disability to ensure they were accessible and that the case management was adapted. Support from a disabled people's organisation or an organisation of people living with HIV was also offered.

---

[28] Wolting R. 2011. Challenges and Solution Strategies for Early Identification and Early Intervention in the Framework of CBR Programmes, In Inclusive Early Childhood Development – an Underestimated Component within Poverty Reduction, Disability and Development Cooperation, Caritas international/Germany, Kindermissionswerk, "Die Sternsinger" Kindernothilfe (eds.): p.143-153.
http://www.bezev.de/fileadmin/Neuer_Ordner/Literatur/Bibliothek/Publikationen/Inclusive_Early _Childhood_Development_Tagungsdokumentation.pdf

Recommendation 5 - Ensure the security of personal and/or sensitive data at all stages of the activity

The security of personal and sensitive data must be guaranteed at all stages of data management[29], as this kind of data could harm the subjects (risk of being stigmatised, rejection by the family or community, loss of employment or even a risk for their physical security). The measures put in place will vary according to the type of risk, the level of confidentiality required and the data collection modalities adopted (paper or digital, with tablets and smartphones, for example). In the case of aggregated data, the measures to be taken are less restrictive, as the personal dimension is removed and with it the possibility of identification.

Guaranteeing the security of data is essential for:
- Ensuring the confidentiality of the information and thus respecting the subjects' privacy and ensuring their protection;
- Preventing the divulgation of sensitive information that could be used for purposes other than the study.

The confidentiality of personal and sensitive data must be ensured at every stage of data management:

- **Confidentiality during data collection**
  Face-to-face interviews are best, with no third-parties present and in a place where the interview cannot be overheard (by family, neighbours, etc.) Yet these simple recommendations can sometimes be difficult to implement because of the intervention context (e.g. in emergency situations), cultural norms (e.g. talking to a woman without her husband present) or because of the need for special assistance (e.g. people with intellectual disabilities). Data collection agents must be sensitive to these confidentiality issues, as the privacy and security of subjects must be protected to the greatest extent possible.

- **Confidentiality during data processing (anonymisation, codification)**
  It may be necessary to codify information to guarantee the confidentiality of the data collected. This may involve anonymising the data base, i.e. using identification numbers in place of nominative identifiers. In this case, a source file with a back-up of the correspondences between names and numbers should be kept separate from the database. These data anonymisation methods should be explained in the study/research protocol.

---

[29] See Figure 1 in this guidance note : data management includes the preparation, collection, processing and analysis of data and the sharing of the new information produced.

- **Ensuring the security of shared reports**

  The findings will of course be shared, either internally or externally (donor reports, scientific publications, etc.). Data is usually aggregated, but for testimony or qualitative research with verbatim text[30], for example, it is important not to give any indications that could help identify the subjects.

- **Secure data transfer**

  Data transfer is a vast issue for an international organisation, as it is also dependent on sometimes complex internal procedures and technical constraints. When transferring paper documents containing personal and/or sensitive data from the field to head office, postal services can be unsafe (risk of the documents going astray, being checked or misappropriated). It is safer entrusting them to expatriates. When sending digital documents (by internet, for example), and depending on the risks associated with the data, use a secure system and/or data encryption mechanisms and limit the number of recipients.

- **Secure data archiving and retention**

  Data retention issues concern paper and digital media. Depending on the context, reinforced protection systems should be used for highly sensitive data. However, some basic measures can provide a first line of security:
  - Identify who is to be in charge of the various media, their prerogatives and level of access (field programme director, coordinator, project manager, partners, etc.);
  - Paper documents (questionnaires, transcripts of qualitative interviews) should be kept in a safe and secure place (locked cupboard, safe, etc.) during the data collection and analysis stages and destroyed once the study is over (permanent disposal), with the data backed up on a database;
  - For digital media (database, transcripts of interviews or testimony, etc.), secure the documents with a password and limit the number of back-ups and people with access to sensitive data;
  - Define how long the data must be kept (i.e. minimum retention period) and how long it can be kept (i.e. maximum retention period)
  - Lastly put clear procedures in place for protecting or destroying the information in the event of an evacuation or withdrawal from the field (notably in sensitive contexts).

---

[30] *Verbatim texts* are word for word quotes taken from interviews and usually accompanied by a few characteristics of the person who has spoken (gender, age, profession...).

>•< Images and communication

The use of image media is also bound by ethical principles. Handicap International's Federal Communication Department has issued an internal memo outlining the principles governing the organisation's use of beneficiaries' testimony and photos for fundraising purposes. It advises against using photos of degrading situations, dead people or nude or partially-clothed bodies. People's dignity and modesty must be preserved in all photos. In no circumstances should they be exploited for their shock value.

Recommendation 6 - Plan and guarantee the use and sharing of information

Often too much data is collected in the field. As it is never analysed or used, this is a waste of the teams' and subjects' time and energy.

To remedy this, there are a number of important points to be verified before starting:

- The data collected should be relevant and in phase with the objectives and end purposes of the study. When developing data collection tools, any questions that don't contribute towards the objectives should be removed.

- The data collected is to be analysed and interpreted. It is therefore essential to take future analyses into account when developing the data collection tools. The time and skills needed for data analysis and interpretation should also be anticipated. The findings should be accompanied by a narrative description interpreting them in light of the context and the objectives established.

- All data collected should be used. Data collection is not an aid action in itself; the information generated must satisfy clear objectives and be used for pre-defined purposes (action, operational purposes, advocacy and/or impact and accountability).

- The information generated should be disseminated and shared. Defining a dissemination plan at the outset of an activity helps ensure the effective use of information. The results and information will need "translating" according to the public targeted: humanitarian or development experts are not addressed in the same way as civil society representatives or researchers, for example. The media (scientific reports, briefs, public meetings, etc.), key messages and confidentiality levels required (names in testimony, faces in photos, etc.) should also be adapted to the targets (feedback to beneficiaries, internal or external, experts or general public, etc.) and the objectives (reporting, advocacy, etc.).

> **➤•◄ Using and sharing data: an issue that concerns everyone**
>
> The effective use of findings is a key issue in data management. Both NGOs and donors are endeavouring to improve this aspect. After ascertaining that information generated was not necessarily reaching the actors of change (civil society, media, etc.), DFID published a call for proposals in 2015 on « Improving communication of research evidence for development ». This appeal supports actions that facilitate the sharing of research evidence between researchers (or others) and key actors to inform national development policy and practice.

Recommendation 7 - Ensure the expertise of the teams involved and the scientific validity of the activity

The scientific value[31] of the approach depends on all the stages in information management being properly prepared:

- First, an analysis of existing data (secondary data, crowdsourcing, etc.) should be carried out to establish the existing level of knowledge on the issue/sector to be studied, avoid producing information that is already available and spare the target populations a needless demand on their time and psychological well-being.

- Identifying what will be measured, formulating clear objectives and determining the end purpose of the activity are all essential initial stages. Only when these tasks have been completed can the relevance of the activity be evaluated (usefulness; feasibility in the cultural, political and/or social context; availability of material and human resources, etc.).

- Planning how to go about things, the time frame and the human and financial resources required is equally crucial, as this permits each person's responsibilities at each stage in the data management process to be identified, along with the mechanisms needed to ensure the protection of individuals and data (in conjunction. with recommendations 1 and 5).

Scientific validity also depends on the techniques used in the methods implemented. The translation of data collection tools into local languages, for example, is crucial for guaranteeing that collection modalities are standardised between researchers, that the subjects understand correctly and that the response options are the same from one survey to the next. "Back translation" [32] is the recommended translation technique.

The need to train the data collection agents who will be conducting the interviews has been stressed in all the other recommendations (security of individuals, consent, referral, data security). Data collection skills should also be part of the training provided to prevent imprecise data from being collected or the subjects from being made to feel uncomfortable and omitting or transforming information. The expertise and

---

[31] Scientific is understood here to mean objective, reliable and methodical.
[32] In this method, the translation of the questionnaire from French (or English) into the local language should be done by two bilingual people. The first person translates the questionnaire from French into the local language and the second translates the translated version back into French. The two French versions are then compared and any problems of interpretation discussed and resolved.
Source: Vallerand RJ. 1989. Vers une méthodologie de validation trans-culturelle de questionnaires psychologiques : Implications pour la recherche en langue française, in Canadian Psychology/ Psychologie Canadienne, 30:4 :
http://www.er.uqam.ca/nobel/r26710/LRCS/papers/35.pdf

professionalism of the field actors is what guarantees the quality of the information gathered.

Techniques also concern the processing and analysis of the data collected. With qualitative data, the body of data must be transcribed and subjected to a serious analysis (at least thematic) to ensure that the recorded words are not simply reported, but scrutinised, compared, set in context and interpreted.

All of these elements should be explained in the protocol when preparing the study, data collection or research. But all the stages leading to the production of new information must also be described in a report at the end of a study in order to:
- ensure total transparency about the origin of this information;
- enable third-parties to reproduce the method.

Remember that the data produced may well be used by other actors as secondary data and they will need to know the details of its creation in order to assess its reliability.

A quality approach implemented by qualified actors helps guarantee respect for everyone involved in data management (subjects, aid actors and the public targeted by the findings) and ensure the generation of solid and reliable data, difficult to refute or contest. Therefore, there is no such thing as a "little study" or "a bit of research" that can conducted without using a quality approach and competent teams.

> **>•< Pre- and post-impact studies in the mines sector**
>
> The Arms Risk Reduction Unit provides field teams with a methodology resource kit to help them carry out impact studies as part of their risk education activity. It contains a standard protocol covering all the essential points to be covered (objectives, methodology, time frame, task distribution, etc.) in order to guarantee the reliability of the data produced.

Recommendation 8 - Obtain authorisation from the relevant authorities and organise an external review of the proposed study/research

Studies or research must be carried out in accordance with the rules of international law, and notably with international conventions on human rights, but also with respect to the legal framework in place in the intervention zone. Furthermore, wherever, possible and before beginning to collect data from a population, the goodwill of the local and/or national authorities should be obtained. This will facilitate the process, the authorities' acceptance of the findings and enable any new information generated to be published and disseminated. If the context and/or issues concerned are too sensitive or strategic, a risk analysis should be carried out and a decision taken on the basis of the harm/benefits identified.

For research projects focusing on sensitive issues or including the sampling of human tissue (blood, for example), it is preferable to ask an ethics committee to organise an independent peer review. In fact, this will be mandatory in certain contexts (for example, if blood samples are to be taken as part of study of HIV). This review will look at both technical and ethical aspects. The project will be evaluated in terms of the scientific quality of the proposal, the harm/benefits ratio and the mechanisms to be put in place to ensure the protection of all the actors involved.

According to the context and situation, various types of ethical committee can be engaged:
- national state-based: review by the national ethics committee;
- institutional: review by the ethical committee of a university or organisation;
- specific: review conducted by a committee set up specifically for the project.

Submitting a project to a committee of whatever sort takes time and money. For example, in Senegal, it takes two months for the National Ethics Committee for Research in Health to issue a recommendation, at a cost of 300,000 CFA (or €457) if the budget for the study or research is less than 10,000,000 CFA (or €15n245), and 500,000 CFA (or €762) if the budget is over 10,000,000 CFA (or €15,245).

This review is not compulsory for all Handicap International's projects but, in any case, the ethical considerations outlined in this guidance note should be taken into account. Indeed, certain aspects must never be overlooked, such as the right to refuse to take part and respect for anonymity and confidentiality.

> **Shattered Dreams: living conditions, needs and capacities of the survivors of mines and explosive remnants of war accidents in Mozambique**
>
> The objective of this study was to identify and analyse the needs of survivors of accidents caused by landmines and explosive remnants of war in Inhambane and Sofala provinces (Mozambique). The information generated was used to help the government draft a National Action Plan on Victim Assistance in conjunction with the National Action Plan on Disability. In order to respect the legislative frameworks and ensure the study was conducted in the best possible conditions, consent was first obtained from the Ethical Committee of the Ministry of Health, Ministry for Women and Social Action, National Demining Institute and health and social action directorates of Inhambane and Sofala provinces.

Ethics checklist

This checklist contains all the questions to ask/points to check to ensure that the study/research to be conducted complies with the eight ethical recommendations presented in this guidance note.

Key:

Prepare / Collect / Process / Analyse and Interpret / Share and Use

Stages in the management of the data concerned	Questions to ask		Referral to the relevant recommend-dation
Prepare Collect	**Environment / context**		
	• Are there any risks for the teams in the environment in which the study/research is to be conducted? If so, have the risks been identified and analysed? Have any strategies been put in place to attenuate their effects?	○	Rec.1
Prepare Collect	**Objectives**		
	• Are the topic and objectives of the study clearly formulated?	○	Rec.7
	• Does the study/research raise any strategic issues for Handicap International (policy, advocacy, etc.)?	○	Rec.1
	• Does the study/research meet an identified need for the target population?	○	Rec.2
	• Was a participatory approach used to identify the issue and objectives? Have the most vulnerable been given a voice? Are any groups excluded?	○	Rec.2
	• Is there any existing information on the topic? If so, has the added-value of this study/research been shown?	○	Rec.7
Prepare Share and Use	**End purposes**		
	• Have the end purposes of the study/research, i.e. the planned use of the findings, been defined?	○	Rec.6
	• Is the data to be disseminated externally? If so, has a plan been prepared for the dissemination of the new information generated, including the media/materials to be developed and the communication channels to be mobilised for the end purposed identified?	○	Rec.6

	Target population		

	• Among the people targeted, are there any:
	  - People generally considered incapable of giving their consent?
	  - People below the age of consent?
	  - People who are unable to give written consent?
	If so, have media and messages been made available to inform them and obtain their informed consent on the activity? Have the necessary measures been taken to ensure effective communication?
	If so, are the data-collection techniques adapted?
		○	Rec.2 – Rec.3

	• Has the target population already been solicited to take part in other data-collection activities and is there a risk of weariness/feeling of being over-solicited?	○	Rec.7
	Information provided to the target population		
	• Is the activity liable to create expectations of assistance, or of receiving something in return for taking part?	○	Rec.1
	• Does the information provided when seeking consent clearly define the objectives of the study/research and explain that there are no conditions attached and no obligation to take part?	○	Rec.3
	Sensitivity of the subject and type of data		
	• Will any personal or sensitive data be collected and analysed to meet the objectives identified? If so, is this data essential to the activity?	○	Rec.6
	• Is the data-collection activity liable to cause stress, anxiety or have negative consequences on the subjects? If so, have appropriate and existing services been identified? If so, have the necessary referral mechanisms been identified for the subjects? If so, have the data collection agents been given this information?	○	Rec.1 – Rec.4
	• Is the data-collection activity liable to cause stress, anxiety or have negative consequences on the teams? If so, are discussion and debriefing forums available to the teams?	○	Rec.1
	• Are procedures in place to guarantee confidentiality during the data collection, processing and analysis stages?	○	Rec.5
	• Are procedures in place to guarantee the security of data when stored and transferred?	○	Rec.5

	• Are procedures in place to guarantee the security of data when archived?	○	Rec.5
Methodology of the study/research			
	• Is there a written protocol containing methodology developed for collecting and analysing the data?	○	Rec.7
	• Does the methodology ensure that stated objectives can be precisely met?	○	Rec.7
	• Does the activity use visual or vocal methods that might allow the subjects to be identified?	○	Rec.1 – Rec.5
	• Are any invasive or intrusive procedures planned (administration or vitamins or other products, for example)?	○	Rec.8
	• Does the study or research involve taking tissue samples or biological samples? If so, have the necessary procedures been put in place (anonymity of samples, conservation, transfer to laboratories, etc.)? ?	○	Rec.8
Resources			
	• Do you have access to all the competencies necessary to conduct the study/research?	○	Rec.7
	• Do you have access to all the resources necessary (time, money, material) to conduct the study/research?	○	Rec.7
Training the teams			
	• Is training planned for the data researchers?	○	Rec.7
	• Does it include a module on how to present the study/research and on obtaining consent?	○	Rec.3
	• Does it include a module on the techniques and know-how required for collecting good-quality information?	○	Rec.7
	• Does it include a module on possibilities for referral and the attitude to adopt if a situation is identified?	○	Rec.4
Authorisation and peer review			
	• Is the authorisation of local and/or national authorities necessary to ensure the smooth-running of the activity?	○	Rec.8
	• Is validation by an ethics committee required? If so, has time been allowed for this procedure?	○	Rec.8

	Involvement of other actors (partners, consultants)		
	• Are any partners involved in the activity? Have any consultants been recruited? If so, have they been given this guidance note? If so, has a briefing been arranged for them to explain the recommendations and ensure they have been properly understood?	◯	Rec.7

Studies and research at Handicap International: Promoting ethical data management

This guidance note draws on Handicap International's field experience, but also on reference documents and scientific articles on the ethical issues surrounding the production and analysis of reliable and conclusive data, otherwise known as "evidence", in aid and development settings.

It aims to raise the awareness of Handicap International's operational and technical staff and their partners to the ethical questions to be considered when managing data (preparation, collection, processing, analysis and sharing of information). It reaffirms the ethical principles underpinning the organisation's actions and transposes them into eight ethical recommendations applicable to studies and/or research in our intervention settings. These recommendations are not intended as directives or rigid and restrictive action standards, provided their non-respect does not conflict with other obligations. They should be considered more as markers for guiding action.

HANDICAP INTERNATIONAL