



Module 7

RESEARCH ETHICS:

Social and Cultural Sensitivity

Ragnhild Dybdahl
Centre for Crisis Psychology
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UNIVERSITY OF BERGEN





Learning Outcomes

- 1. Respect diverse cultural perspectives
- 2. Address and critically examine social and cultural implications of research
- 3. Be aware of debate and dilemmas regarding a universality view of research ethics
- 4. Be able to discuss contextual factors associated with all aspects of research ethics



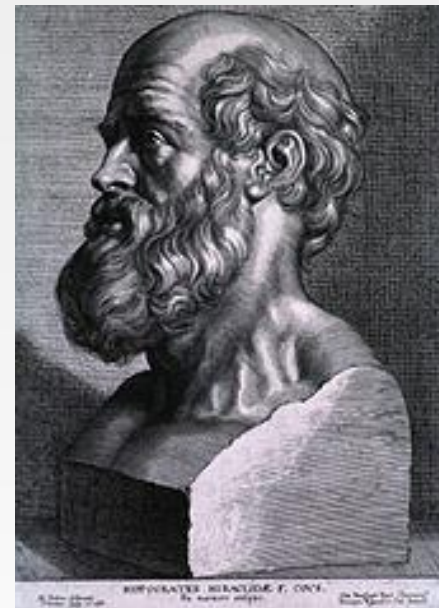


Basic principles

Primum non nocere
First, Do No Harm

Do good
Minimise harm

Justice
Fairness
Dignity
Autonomy



Do no harm



Lack of contextual understanding or consideration can cause harm

nity-based approach to assisting war-affected children. In U. P. Gielen, J. Fish, & J. G. Draguns (Eds.), *Handbook of culture, therapy, and healing* (pp. 321–341). Mahwah, NJ: Erlbaum.

Wessells, M., & Monteiro, C. (2006). Psychosocial assistance for youth: Toward reconstruction for peace in Angola. *Journal of Social Issues, 62*(1), 121–139.

Wessells, M., & Winter, D. (Eds.). (1998). The Graca Machel/UN Study on the effects of war on children [Special issue]. *Peace and Conflict: Journal of Peace Psychology, 4*.

Do No Harm: Toward Contextually Appropriate Psychosocial Support in International Emergencies

Michael G. Wessells
Columbia University and Randolph-Macon College

In the aftermath of international emergencies caused by natural disasters or armed conflicts, strong needs exist for psychosocial support on a large scale. Psychologists have developed and applied frameworks and tools that have helped to alleviate suffering and promote well-being in emergency settings. Unfortunately, psychological tools and approaches are sometimes used in ways that cause unintended harm. In a spirit of prevention and wanting to support critical self-reflection, the author outlines key issues and widespread violations of the do no harm imperative in emergency contexts. Prominent issues include contextual insensitivity to issues such as security, humanitarian coordination, and the inappropriate use of various methods; the use of an individualistic orientation that does not fit the context and culture; an excessive focus on deficits and victimhood that can undermine

Editor's Note

Michael G. Wessells received the International Humanitarian Award. Award winners are invited to deliver an award address at the APA's annual convention. A version of this award address was delivered at the 117th annual meeting, held August 6–9, 2009, in Toronto, Ontario, Canada. Articles based on award addresses are reviewed, but they dif-

fer from the award address. The award address should focus on empowerment and resilience; the use of unsustainable, short-term approaches that breed dependency, create poorly trained psychosocial workers, and lack appropriate emphasis on prevention; and the imposition of outsider approaches. These and related problems can be avoided by the use of critical self-reflection, greater specificity in ethical guidance, a stronger evidence base for intervention, and improved methods of preparing international humanitarian psychologists.

Keywords: psychosocial support, emergencies, unintended harm, resilience, cultural insensitivity

Large-scale emergencies such as tsunamis and armed conflicts create not only massive physical destruction but also an enormous toll of psychological and social suffering (Boothby, Strang, & Wessells, 2006; Cardozo, Talley, Burton, & Crawford, 2004; de Jong, 2002; Marsella, Bornemann, Ekblad, & Orley, 1994; Miller & Rasco, 2004; Mollica, Pole, Son, Murray, & Tor, 1997; Reyes & Jacobs, 2006; van der Kolk, McFarlane, & Weisaeth, 1996; Wilson & Drozdek, 2004) in the low- and middle-income countries where most disasters strike. Prominent sources of suffering include attack, losses of home and loved ones, displacement, family separation, gender-based violence, and exposure to myriad protection issues such as recruitment into armed groups and trafficking.

A decade ago, mental health and psychosocial supports in international emergencies were relegated to the humanitarian ghetto and seen as things to be done after the "real" humanitarian work of saving lives had been completed. This has changed as public awareness of the aftermath of emergencies has increased, and psychosocial supports have become familiar fixtures in the humanitarian response to disasters. More than any other single event, the 2004 Asian tsunami brought home to people worldwide the enormity of the psychosocial needs that emergencies create.

The expanded awareness of the importance of psychosocial intervention has brought an expansion of psychosocial interventions. Many practitioners, myself included, regard this as a positive development, because there is increasing evidence of the efficacy of psychosocial interventions in addressing issues of trauma (e.g., Barbanel & Sternberg, 2006; Carll, 2007; Green et al., 2003), depression (Bolton et al., 2007), family separation (Hepburn, 2006), recruitment (Betancourt et al., 2008), and related issues and in promoting resilience and positive coping by survivors and communities (e.g., Barber, 2009).

At the same time, practitioners increasingly recognize that there are risks involved with psychosocial interventions that may lead to unintentional harm (Anderson, 1999;

Contextual considerations are important in all areas of research ethics

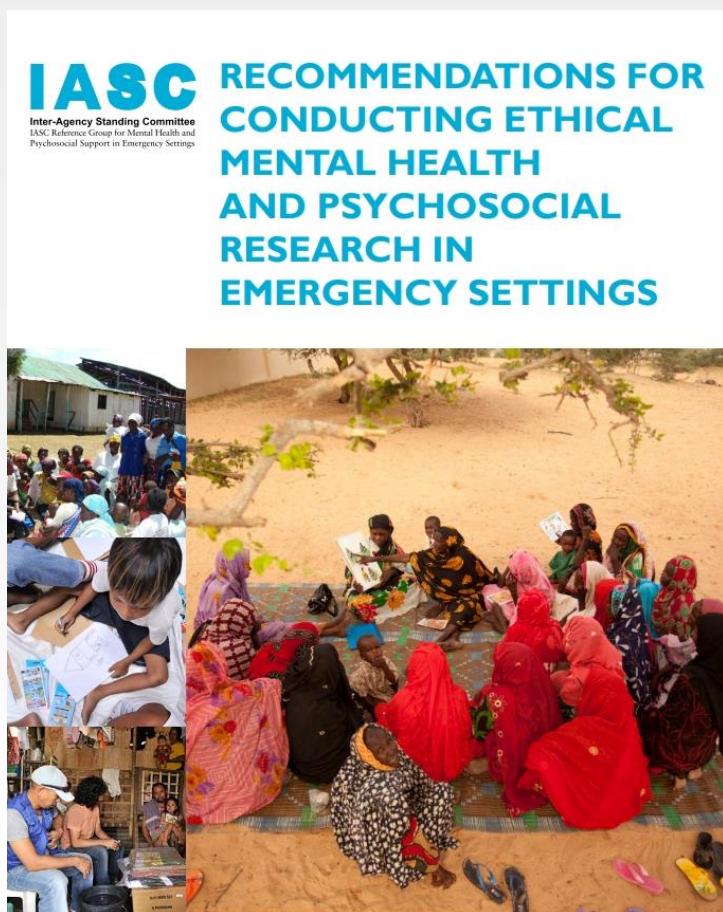
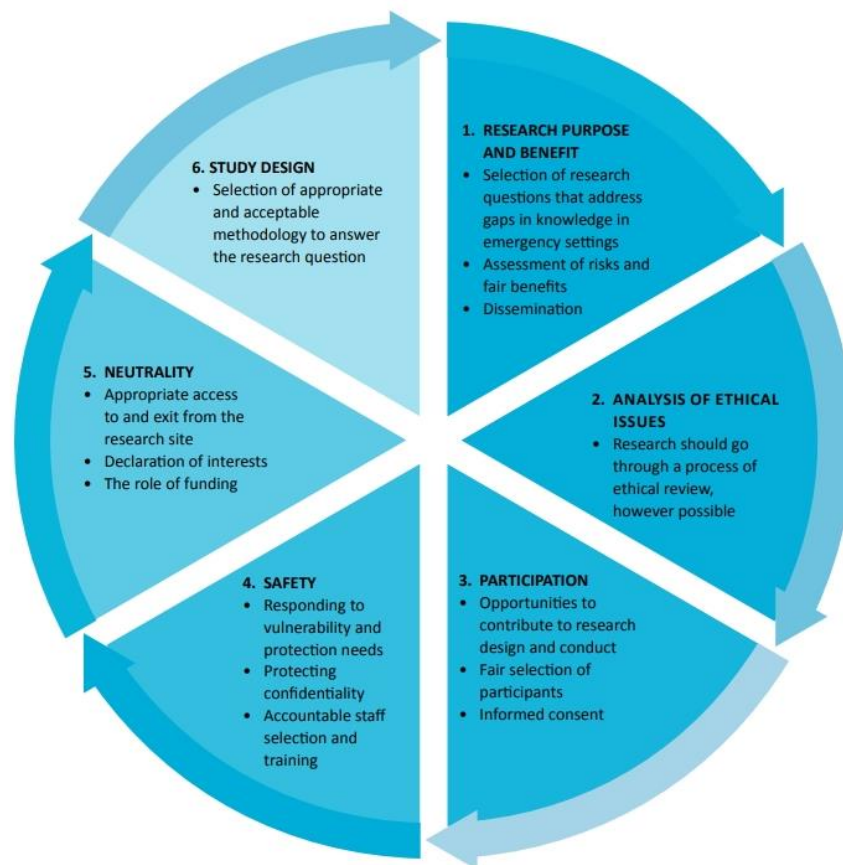


Figure 1. Six key areas covered by the recommendations





Universal research ethics?

- Universalism
- Relativism
- Situated ethics
- Diversity
- Ethics education and training



Original Article: Empirical

One size fits not quite all: Universal research ethics with diversity

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Abstract

For researchers in Aotearoa New Zealand who intend to conduct research with people, it is common practice to first ensure that their proposals are approved by a Human Research Ethics Committee (HREC). HRECs take the role of reviewing, approving or rejecting research proposals and deciding on whether the intended research will be completed in the 'right', rather than the 'wrong' way. Such decisions are based upon a system which is guided by universal ethical principles – principles that assume there is universal agreement about the ethically right way to conduct research. Increasingly, Aotearoa New Zealand is becoming more culturally diverse. Actions that are assumed as 'right' in reference to ethical norms endorsed in one culture or society may not always be considered 'right' in reference to ethical norms in another culture or society. In this article we first set out what is already known in the literature about the origins and applications of universal ethics in a research context. Next, we analyse how cultural values and beliefs bear influence on the process of ethical deliberation. Two case studies illustrate our own examples of how conducting ethical research projects following universal principles with cultural diversity operated in practice. We conclude that one size fits not quite all. Lastly, we propose that Aotearoa New Zealand HRECs may need to consider expanding their approach from universal ethical principles to include a more diverse interpretation of what is 'ethical research conduct'. Rather than advocating a radical approach, i.e. either universality or diversity, it is time for HRECs to

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“If dignity is to have any meaning at all, it must honor the perspective of those affected...”

Consider the perspective of one Rwandan informant talking to writer Andrew Solomon:

We had a lot of trouble with Western mental health workers who came here immediately after the genocide and we had to ask some of them to leave. They came and their practice did not involve being outside in the sun where you begin to feel better. There was no music or drumming to get your blood flowing again. There was no sense that everyone had taken the day off so that the entire community could come together to try to lift you up and bring you back to joy. There was no acknowledgement of the depression as something invasive and external that could actually be cast out again. In stead, they would take people one at a time into these dingy little rooms and have them sit around for an hour or so and talk about bad things that had happened to them. We had to ask them to leave.


Dyer, A. (2019). Global mental health: Ethical principles and practices. George Washington University Department of Psychiatry Grand Rounds, November 21, 2019

The TRUST Code

A Global Code of Conduct for Equitable Research Partnerships



The TRUST Code
A Global Code of Conduct for Equitable Research Partnerships



Research partnerships between high-income and lower-income settings can be highly advantageous for both parties. Or they can lead to ethics dumping, the practice of exporting unethical research practices to lower-income settings.

This Global Code of Conduct for Equitable Research Partnerships counters ethics dumping by:

- Providing guidance across all research disciplines
- presenting clear, short statements in simple language to achieve the highest possible accessibility
- focusing on research collaborations that entail considerable imbalances of power, resources and knowledge
- using a new framework based on the values of fairness, respect, care and honesty

- offering a wide range of learning materials and affiliated information to support the Code, and
- complementing the European Code of Conduct for Research Integrity through a particular focus on research in resource-limited settings.

Those applying the Code oppose double standards in research and support long-term equitable research relationships between partners in lower-income and high-income settings based on fairness, respect, care and honesty.

The TRUST Code
A Global Code of Conduct for Equitable Research Partnerships



www.globalcodeofconduct.org/



[Home - The TRUST Code](#) TRUST (2018) The TRUST Code

– A Global Code of Conduct for Equitable Research Partnerships, DOI: <https://doi.org/10.48508/GCC/2018.05>



FAIRNESS



ARTICLE 1

Local relevance of research is essential and should be determined in collaboration with local partners. Research that is not relevant in the location where it is undertaken imposes burdens without benefits.

ARTICLE 2

Local communities and research participants should be included throughout the research process, wherever possible, from planning through to post-study feedback and evaluation, to ensure that their perspectives are fairly represented. This approach represents Good Participatory Practice.

ARTICLE 3

Feedback about the findings of the research must be given to local

communities and research participants. It should be provided in a way that is meaningful, appropriate and readily comprehended.

ARTICLE 4

Local researchers should be included, wherever possible, throughout the research process, including in study design, study implementation, data ownership, intellectual property and authorship of publications.

ARTICLE 5

Access by researchers to any biological or agricultural resources, human biological materials, traditional knowledge, cultural artefacts or non-renewable resources such as minerals should be subject to the free and prior informed consent of the owners or custodians. Formal agreements should govern the transfer of any material or knowledge to researchers, on terms that are co-developed with resource custodians or knowledge holders.

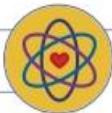
ARTICLE 6

Any research that uses biological materials and associated information such as traditional knowledge or genetic sequence data should clarify to participants the potential monetary and non-monetary benefits that might arise. A culturally appropriate plan to share benefits should be agreed to by all relevant stakeholders, and reviewed regularly as the research evolves. Researchers from high-income settings need to be aware of the power and resource differentials in benefit-sharing discussions, with sustained efforts to bring lower-capacity parties into the dialogue.

ARTICLE 7

It is essential to compensate local research support systems, for instance translators, interpreters or local coordinators, fairly for their contribution to research projects.

RESPECT



ARTICLE 8

Potential cultural sensitivities should be explored in advance of research with local communities, research participants and local researchers to avoid violating customary practices. Research is a voluntary exercise for research participants. It is not a mission-driven exercise to impose different ethical values. If researchers from high-income settings cannot

agree on a way of undertaking the research that is acceptable to local stakeholders, it should not take place.

ARTICLE 9

Community assent should be obtained through recognized local structures, if required locally. While individual consent must not be compromised, assent from the community may be an ethical prerequisite and a sign of respect for the entire community. It is the responsibility of the researcher to find out local requirements.

ARTICLE 10

Local ethics review should be sought wherever possible. It is of vital importance that research projects are approved by a research ethics committee in the host country, wherever this exists, even if ethics approval has already been obtained in the high-income setting.

ARTICLE 11

Researchers from high-income settings should show respect to host country research ethics committees.

CARE



ARTICLE 12

Informed consent procedures should be tailored to local requirements to achieve genuine understanding and well-founded decision-making.

ARTICLE 13

A clear procedure for feedback, complaints or allegations of misconduct must be offered that gives genuine and appropriate access to all research participants and local partners to express any concerns they may have with the research process. This procedure must be agreed with local partners at the outset of the research.

ARTICLE 14

Research that would be severely restricted or prohibited in a high-income setting should not be carried out in a lower-income setting. Exceptions might be permissible in the context of specific local conditions (e.g. diseases not prevalent in high-income countries).

If and when such exceptions are dealt with, the internationally acknowledged compliance commandment "comply or explain" must be used, i.e. exceptions agreed upon by the local stakeholders and researchers must be explicitly and transparently justified and made easily accessible to interested parties.

ARTICLE 15

Where research involvement could lead to stigmatization (e.g. research on sexually transmitted diseases), incrimination (e.g. sex work), discrimination or indeterminate personal risk (e.g. research on political beliefs), special measures to ensure the safety and wellbeing of research participants need to be agreed with local partners.

ARTICLE 16

Ahead of the research it should be determined whether local resources will be depleted to provide staff or other resources for the new project (e.g. nurses or laboratory staff). If so, the implications should be discussed in detail with local communities, partners and authorities and monitored during the study.

ARTICLE 17

In situations where animal welfare regulations are inadequate or non-existent in the local setting compared with the country of origin of the researcher, animal experimentation should always be undertaken in line with the higher standards of protection for animals.

ARTICLE 18

In situations where environmental protection and biorisk-related regulations are inadequate or non-existent in the local setting compared with the country of origin of the researcher, research should always be undertaken in line with the higher standards of environmental protection.

ARTICLE 19

Where research may involve health, safety or security risks for researchers or expose researchers to conflicts of conscience, tailored risk management plans should be agreed in advance of the research between the research team, local partners and employers.

HONESTY



ARTICLE 20

A clear understanding should be reached among collaborators with regard to their roles, responsibilities and conduct throughout the research cycle, from study design through to study implementation, review and dissemination. Capacity-building plans for local researchers should be part of these discussions.

ARTICLE 21

Lower educational standards, illiteracy or language barriers can never be an excuse for hiding information or providing it incompletely. Information must always be presented honestly and as clearly as possible. Plain language and a non-patronising style in the appropriate local languages should be adopted in communication with research participants who may have difficulties comprehending the research process and requirements.

ARTICLE 22

Corruption and bribery of any kind cannot be accepted or supported by researchers from any countries.

ARTICLE 23

Lower local data protection standards or compliance procedures can never be an excuse to tolerate the potential for privacy breaches. Special attention must be paid to research participants who are at risk of stigmatization, discrimination or incrimination through the research participation.





EXAMPLE:

The San Code - The TRUST Code

- The [San Code of Research Ethics](#) was launched in Cape Town in March 2017, more than a year earlier than the *TRUST Code*. It was the first time that an indigenous group in Africa had launched their own ethics code.





https://youtu.be/b4FgXnLKs_0

- RESPECT
- HONESTY
- JUSTICE
- FAIRNESS
- CARE
- PROCESS





San-Code-of-RESEARCH-Ethics-Booklet_English.pdf

RESPECT

We require respect, not only for individuals but also for the community.

We require respect for our culture, which also includes our history. We have certain sensitivities that are not known by others. Respect is shown when we can input into all research endeavours at all stages so that we can explain these sensitivities.

Respect for our culture includes respect for our relationship with the environment.

Respect for individuals requires the protection of our privacy at all times.

Respect requires that our contribution to research is acknowledged at all times.

Respect requires that promises made by researchers need to be met.

Respectful researchers engage with us in advance of carrying out research. There should be no assumption that San will automatically approve of any research projects that are brought to us.

We have encountered lack of respect in many instances in the past. In Genomics research, our leaders were avoided, and respect was not shown to them. Researchers took photographs of individuals in their homes, of breastfeeding mothers, or of underage children, whilst ignoring our social customs and norms. Bribes or other advantages were offered.

Failure by researchers to meet their promises to provide feedback is an example of disrespect which is encountered frequently.



HONESTY

We require honesty from all those who come to us with research proposals.

We require an open and clear exchange between the researchers and our leaders. The language must be clear, not academic. Complex issues must be carefully and correctly described, not simply assuming the San cannot understand. There must be a totally honest sharing of information.

Open exchange should not patronise the San. Open exchange implies that an assessment was made of possible harms or problems for the San resulting from the research and that these possible harms are honestly communicated.

Prior informed consent can only be based on honesty in the communications, which needs to be carefully documented. Honesty also means absolute transparency in all aspects of the engagement, including the funding situation, the purpose of the research, and any changes that might occur during the process.

Honesty requires an open and continuous mode of communication between the San and researchers.

We have encountered lack of honesty in many instances in the past. Researchers have deviated from the stated purpose of research, failed to honour a promise to show the San the research prior to publication, and published a biased paper based upon leading questions given to young San trainees. This lack of honesty caused much damage among the public, and harmed the trust between the collaborating organisation and the San.

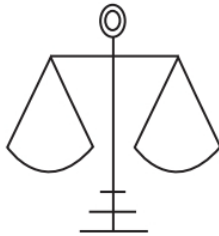
Another common lack of honesty is exaggerated claims of the researcher's lack of resources, and thus the researchers' inability to provide any benefits at all.





San-Code-of-RESEARCH-Ethics-Booklet English.pdf

JUSTICE AND FAIRNESS



We require justice and fairness in research.

It is important that the San be meaningfully involved in the proposed studies, which includes learning about the benefits that the participants and the community might expect. These might be largely non-monetary but include co-research opportunities, sharing of skills and research capacity, and roles for translators and research assistants, to give some examples.

Any possible benefits should be discussed with the San, in order to ensure that these benefits do actually return to the community.

As part of justice and fairness the San will try to enforce compliance with any breach of the Code, including through the use of dispute resolution mechanisms.

In extreme cases the listing and publication of unethical researchers in a "black book" might be considered. An institution whose researchers fail to comply with the Code can be refused collaboration in future research. Hence, there will be "consequences" for researchers who fail to comply with the Code.

We have encountered lack of justice and fairness in many instances in the past. These include theft of San traditional knowledge by researchers. At the same time, many companies in South Africa and globally are benefitting from our traditional knowledge in sales of indigenous plant varieties without benefit sharing agreements, proving the need for further compliance measures to ensure fairness.

CARE

Research should be aligned to local needs and improve the lives of San. This means that the research process must be carried out with care for all involved, especially the San community.

The caring part of research must extend to the families of those involved, as well as to the social and physical environment.

Excellence in research is also required, in order for it to be positive and caring for the San. Research that is not up to a high standard might result in bad interactions, which will be lacking in care for the community.

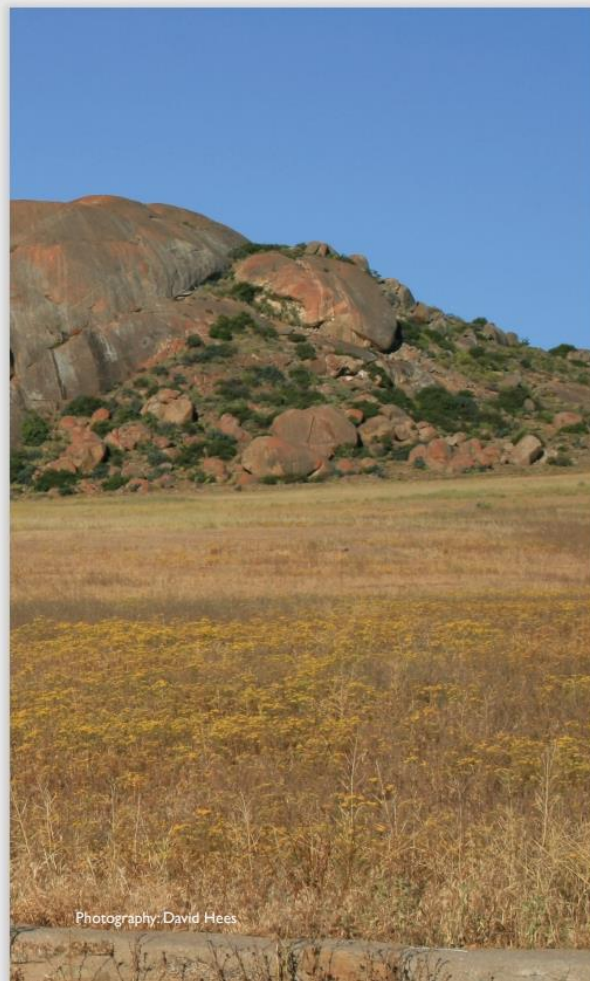
Caring research needs to accept the San people as they are, and take note of the cultural and social requirements of this Code of Ethics.

We have encountered lack of care in many instances in the past. For instance, we were spoken down to, or confused with complicated scientific language, or treated as ignorant. Failing to ensure that something is left behind that improves the lives of the San also represents lack of care.





San-Code-of-RESEARCH-Ethics-Booklet English.pdf



PROCESS Researchers need to follow the processes that are set out in our research protocols carefully, in order for this Code of Ethics to work.

The San research protocol that the San Council will manage is an important process that we have decided on, which will set out specific requirements through every step of the research process.

This process starts with a research idea that is collectively designed, through to approval of the project, and subsequent publications.

The San commit to engaging fairly with researchers and manage effectively all stages of the research process, as their resources allow. They also commit to respecting the various local San structures (e.g. Communal Property Association, CPA leaders) in their communications between San leaders and San communities.

Andries Steenkamp, the respected San leader who contributed to this Code of Ethics until he passed away in 2016, asked researchers to come through the door, not the window.

The door stands for the San processes. When researchers respect the door, the San can have research that is positive for us.



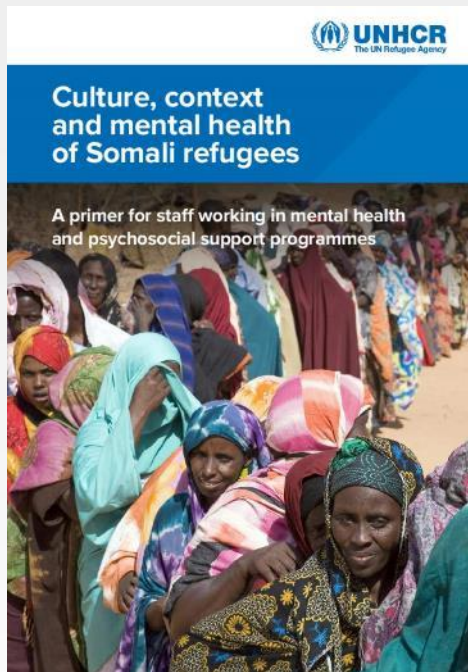
Contact Details: admin@sasi.org.za

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Kimberley Road, Kimberley,
Northern Cape, South Africa.





EXAMPLE: Cultural Considerations and Awareness is crucial in identifying and managing mental health conditions



Chapter

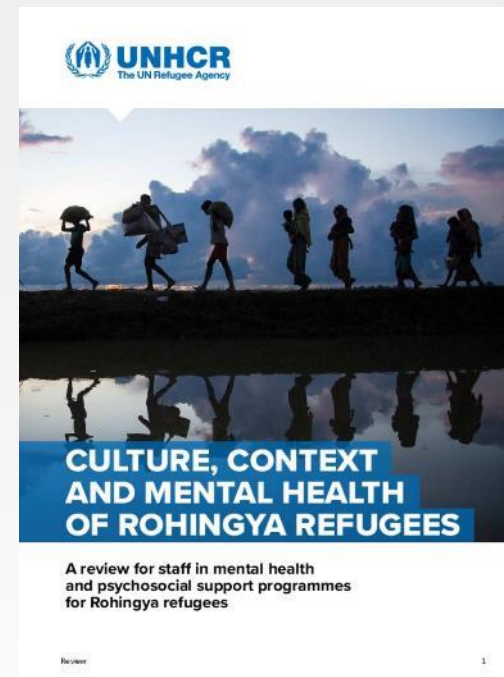
Mpyangu, Christine Mbabazi. 2014. "Ritual and Reintegration of Young Women Formerly Abducted as Children in Northern Uganda". In Doris Buss et.al. Sexual Violence in Conflict and Post Conflict Scenarios: Africa and International Agenda

Conflict Scenarios: Africa and International Agenda · Chapter: 7 · Publisher: Routledge · Editors: Doris Buss et.al

Authors:



Christine mbabazi mpyangu
Makerere University





For consideration

- Consider ethical merit from both a contextual (local) and a technical/scientific perspective, e.g. design and method
- Show how explanation and justification of the topic and methods are adapted to local context
- Language and terms (e.g. childhood)
- Show how contextual norms have been addressed
- Informed consent should be contextually appropriate while maintaining ethical standard
- Consider issues of individual/community, gender, religion, age, sensitivity, historical, stigma





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