

Research with, not about, communities



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Ethical guidance

towards empowerment in collaborative research

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“The foreigner sees what he already knows.”
African proverb



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Executive Summary and Introduction

Community engagement is an ethical imperative (a ‘must’) for researchers operating globally. Research participants, their local communities and research partners in international locations should be equal stakeholders¹ in the pursuit of research-related gains.^{2,3}

In the 1990s, community engagement became prominent as the new guiding light of public health efforts. Involving communities in research and health-improvement programs led to better results than government-led programs alone.⁴ At the same time, the emerging need to protect indigenous communities in genetic research led Canadian Charles Weijer to demand a fifth principle in bioethics^{5,6}: protection for communities.⁷ The individualistic nature of existing research ethics principles, stemming from US origins with its traditional emphasis upon *individual* autonomy was thus questioned. Asian and African ethicists added their voices to highlight the importance of respect for communities, as well as individuals.^{8,9}

This report provides guidance on community engagement in research from the perspective of the four TRUST values: fairness, respect, care and honesty.

These values were identified by a global group of experts as the cornerstones of equitable research partnerships between high-income country (HIC) and low- and middle-income country (LMIC) research partners in any discipline¹⁰. The group included representatives from two vulnerable populations that carry a high burden of research: Kenyan sex workers and San indigenous peoples of Southern Africa. The guidance is suitable for all who support vulnerable populations involved in research projects, including civil society organisations, whether or not they are carrying out the research projects themselves.



¹ ‘Stakeholders’ is an increasingly contested term, as it may imply that all parties hold an equal stake. Some prefer the term ‘actors’, yet this brings its own complexities. Acknowledging the debate, we use the well-established term stakeholders throughout.

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3483026/>

³ <http://www.tandfonline.com/doi/full/10.1080/13648470.2015.1081670>

⁴ https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

⁵ Tom L. Beauchamp and James F. Childress (2012) *Principles of Biomedical Ethics*, Seventh Edition, Oxford: Oxford University Press.

⁶ The first four principles following Beauchamp and Childress are: non-maleficence, beneficence, justice and autonomy.

⁷ <http://www.unige.ch/medecine/ieh2/files/1414/3472/9181/me-8-Emanuel-protecting-communities-in-research.pdf>


⁸ Tangwa, Godfrey (1999) Globalisation or Westernisation? *Bioethics* (13) 3/4: 218-226.

⁹ Hoshino Kazumasa (ed) (1997) *Japanese and Western bioethics: studies in moral diversity*. Kluwer Academic Publishers; Dordrecht: 1997.

¹⁰ See: www.globalcodeofconduct.org

The report is based on:

- relevant published literature,
- the experience of the research and humanitarian assistance work of *Action against Hunger* (ACF),
- input from over-researched sex workers and indigenous peoples' representatives,
- input from researchers in both academia and industry,
- research ethics committee chairs and members from India and Kenya,
- research funders, and
- civil society organisations.



Our main advice is to build *long-term, mutually beneficial relationships* based on the values of fairness, respect, care and honesty, to apply *before, during and after* research studies.



South African Kalahari, San house¹¹

¹¹ Photos in the report are from community engagement conducted by members of the TRUST team over the last 10 years to emphasize the importance of building long-term relationships.

Communities and Engagement

“Whether to engage with communities or not is an ethical question. Engagement is not a benchmark for ethics. Ethics does not stop when community engagement takes place. Engagement itself has ethical implications.”¹²

The term ‘community’ is contentious, contextual, and can be difficult to define.¹³ For the purposes of this report, we use an early definition from the World Health Organization (1998), which describes a community as:

*A specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social structure according to relationships which the community has developed over a period of time. Members of a community gain their personal and social identity by sharing common beliefs, values and norms which have been developed by the community in the past and may be modified in the future.*¹⁴

As we can infer from this definition, there are many different types of communities and also communities within communities. For example, indigenous communities, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, may consider themselves distinct from other sectors of the societies that now prevail on those territories, or parts of them. They generally form non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity. In doing so, they hope to provide the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal systems.¹⁵ They often have particular relationships with advocacy groups who work to protect or represent their interests.¹⁶

Community from the Latin word *Communitas*:
a community spirit, the feeling of social equality, solidarity, and togetherness.



The concept of communities within communities also includes groups or communities of people who are vulnerable because of a range of physical (disabilities, for example) or cultural (religion, for example) characteristics. For instance, sex workers, injecting drug users, or men who have sex with men, are often marginalized within their own communities (where community can mean the village/town/city/ethnic group, etc.). For these and other vulnerable groups, the community at large or the community leaders cannot be expected to provide the input needed to ensure relevant ethical management of research. Communities and their leaders may be unaware of the specific circumstances of these people and their lives, but they may also be openly hostile.

¹² https://wellcome.ac.uk/sites/default/files/wtvm054326_0.pdf

Community Engagement – Under the Microscope 2011

¹³ Day, Graham (2006) *Community and Everyday Life*. London: Routledge.

¹⁴ <http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf>, page 5.

¹⁵ Cobos, Martinez (2014) Study on the Problem of Discrimination against Indigenous Population. Available at <https://www.un.org/development/desa/indigenouspeoples/publications/2014/09/martinez-cobo-study/>

¹⁶ Advocacy groups (also known as pressure groups, lobby groups, campaign groups, interest groups, or special interest groups) use various forms of advocacy in order to influence public opinion and/or policy. For a useful definition see https://en.wikipedia.org/wiki/Advocacy_group Throughout this report we use the term *advocacy group* to refer to any organisation which would recognise itself as such.

However, in the 21st century, community is not always restricted in this traditional geographical sense. Groups outside the mainstream such as refugees, lesbians at risk of violence, or sex workers with disabilities may not be geographical communities, but may constitute themselves as, for example, displaced or online communities, and are often the subjects of international research.^{17,18}

We therefore need to rely on structures that can legitimately speak on behalf of these marginalized and very vulnerable populations, through mechanisms such as advocacy groups, where these exist. In the context of HIV, for example, the notion of “community-driven research” has led to multiple studies being carried out at the request of HIV advocacy groups, to answer questions that they had identified. They have found scientific partners to help them design and carry out studies which would benefit the community to ensure their scientific quality.

Effective community engagement can ensure that all voices are heard and opinions represented in equal measure.

In the TRUST project, we are particularly interested in how vulnerable¹⁹ communities in LMICs can become equitably engaged in collaborative research ventures with HIC partners. These could be indigenous communities; rural communities (for example, Sub-Saharan Africa subsistence farmers); or communities held together by a shared occupation, physical or psychological feature, or behaviour (such as sex workers in Kenya, albino people etc.). Regardless of the types of communities, the important point is that when funders, researchers, ethics committees, potential research participants and local communities come together for research purposes, they bring with them an array of experiences and opinions that shape the way they interact with one another and the way they view the research. In such circumstances, effective community engagement can ensure that all voices are heard and opinions represented in equal measure.



Community engagement in the Kalahari (partners from the TRUST project: research meeting to understand how the benefits of the Hoodia plant can be equitably distributed (partners from the TRUST project, UCLan, SASI, UCT)

¹⁷ https://wellcome.ac.uk/sites/default/files/wtvm054326_0.pdf

Community Engagement – Under the Microscope 2011 p15

¹⁸ WHO. Track 1: Community empowerment 7th Global Conference on Health Promotion: Track themes <http://www.who.int/healthpromotion/conferences/7gchp/track1/en/>


¹⁹ Schroeder D, Gefenas E, Vulnerability: Too vague and too broad? Cambridge Quarterly of Healthcare Ethics, 18:113-121

Just as appreciation of the benefits of community engagement in public health have grown, so too the benefits of community engagement in research are now widely acknowledged. Numerous publications describe many potential benefits of community engagement in research, such as increasing community understanding and acceptance of the studies; enhancing researchers' ability to understand and address community priorities; improving logistics and running of studies; strengthening the quality of the information that is collected; ensuring culturally sensitive communications and research approaches; and enhancing opportunities for capacity building.^{20,21,22,23}

Ahmed and Palermo provide a salient definition of community engagement in research as:
*a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus.*²⁴

To be effective, community engagement in international research requires the development of partnerships with 'local' (for example, national/regional/affinity or advocacy group) stakeholders²⁵, involving them in assessing local challenges and research priorities, determining the value of research, planning, conducting and overseeing research, and integrating the results with local needs where relevant.²⁶ Moreover, it requires members of the research team to become part of the community and members of the community to become part of the research team to create bespoke working environments before, during and after the research.¹⁴

Members of the community should become part of the research team to create bespoke working environments **before, during and after the research.**



There are many proposed models for community engagement in research²⁷. Here we highlight the primary ethical considerations for organisations or researchers when engaging

²⁰ Hebert, J. R., Brandt, H. M., Armstead, C. A., Adams, S. A., & Steck, S. E. (2009). Interdisciplinary, Translational, and Community-Based Participatory Research: Finding a Common Language to Improve Cancer Research. *Cancer Epidemiology, Biomarkers & Prevention*, 18(4), 1213–1217. <http://doi.org/10.1158/1055-9965.EPI-08-1166>

²¹ Cook, W. K. (2008). Integrating Research and Action: A Systematic Review of Community-based Participatory Research To Address Health Disparities In Environmental and Occupational Health in the United States. *Journal of Epidemiology and Community Health*, 62(8), 668–676. <http://doi.org/10.1136/jech.2007.067645>

²² Bassler, A., Brasier, K., Fogel, N. and Taverno, R., 2008. *Developing effective citizen engagement: A how-to guide for community leaders*. Center for Rural Pennsylvania.

²³ https://wellcome.ac.uk/sites/default/files/wtvm054326_0.pdf

Community Engagement – Under the Microscope 2011

²⁴ Ahmed, S. M., & Palermo, A.-G. S. (2010). Community Engagement in Research: Frameworks for Education and Peer Review. *American Journal of Public Health*, 100(8), 1380–1387. <http://doi.org/10.2105/AJPH.2009.178137>

²⁵ See footnote a re terminology.

²⁶ Jones, L. and Wells, K., 2007. Strategies for academic and clinician engagement in community-participatory partnered research. *Jama*, 297(4), pp.407-410.

²⁷ Examples include: community-based participatory research, empowerment evaluation, community action research, and participatory rapid appraisal.

with communities over the course of a research project, through reference to the four TRUST values.



Community visit in Manila (partners from the TRUST project: UCLan, SASI)

The four TRUST Values

Values: *the beliefs people have, especially about what is right and wrong and most important in life, that influences their behaviour.*

In TRUST we refer to values as the foundation of our ethical standpoint in collaborative research.²⁸ Values inspire, motivate and engage people to discharge obligations or duties.²⁹

Our work has shown that some values are shared by communities around the world.³⁰ Through our global engagement activities we have identified four values that are of key importance in collaborations: fairness, respect, care and honesty.

Fairness

Fairness (or justice) can have a number of interpretations but the most relevant concepts for collaborative research ethics are *fairness in exchange*, and *corrective fairness*. In collaborations, as the name indicates, at least two parties are involved in a range of transactions. Issues that need to be considered for fairness in exchange might include the opportunities and allocation of benefits from the research for all parties.

Corrective fairness is about how to right a wrong and includes considerations such as liability and accountability. This type of fairness is vital in collaborative ventures but can be challenging because it is dependent upon the availability and applicability of legal instruments

Fairness: *The quality of treating people equally or in a way that is right or reasonable that influence their behaviour.*

²⁸ <http://trust-project.eu/wp-content/uploads/2016/12/TRUST-Deliverable-Generic-Risks-Final-copy.pdf>

²⁹ <https://plato.stanford.edu/entries/value-theory/>

³⁰ This is in contrast to applied ethical principles that appear to have greater affinity with some cultures than others. For a definition of the four TRUST values see: <http://trust-project.eu/wp-content/uploads/2016/12/TRUST-Deliverable-Generic-Risks-Final-copy.pdf>

and access to mechanisms to right a wrong (for example, a complaints procedure, a court, an ethics committee).

Respect: Due regard for the customs, wishes or rights of others.

Respect

To show respect when engaging with communities requires an acceptance that customs and cultures may be different, and that researchers should behave in a way that does not cause offence. It means that one may need to accept a decision or a way of approaching a matter, even if one disagrees. Respect is therefore also a difficult value, as there

is always the possibility that one *cannot* accept another's decision, especially when this creates a serious conflict of conscience.³¹ To find an appropriate route between imperialist-type imposition of approaches and careless acceptance of human rights violations may sometimes be challenging, but it is what researchers with integrity must sometimes address.

Care

As a priority, care should be taken of those enrolled in research studies to the extent that their welfare is prioritised over any other goals. In line with Article 8 of the *Declaration of Helsinki* this means: *While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects.*³²

Care means to have regard, affection or consideration for.

The values of care applies across disciplines, not just in medical research and is not restricted to human research participants. Article 21 of the *Declaration of Helsinki* extends the care for welfare to research animals.³³ Likewise, care for environmental protection and sustainability is increasingly included in research ethics processes and frameworks for responsible research.³⁴

Researchers who take good care combine two elements: they care about research participants, in the sense that they are important to them, *and* they feel responsible for the welfare of those who contribute to their research, or might suffer as a result of it (including animals and the environment).

Honesty means being truthful and trustworthy

Honesty

Honesty is a value that does not need complicated explanations or definitions. In all cultures and nations, 'do not lie' is a basic prerequisite for ethical human interaction. However, what does need explaining is the scope of the value of honesty in the context of global research ethics.

³¹ https://link.springer.com/chapter/10.1007/978-3-319-64731-9_2

³² <http://www.wma.net/en/30publications/10policies/b3/>

³³ Ibid.

³⁴ <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics>

Lying is only one possible wrongdoing in the context of a broad understanding of honesty. For instance, in research ethics it is equally unacceptable to omit important information from an informed consent process. For this reason, research ethicists often use the terms *transparency* or *open communication* to ensure that all relevant information is provided so that research participants can make an informed choice about participating or not. Importantly, honesty is also related to research conduct other than interaction with research participants. Most prominently, the duties of honesty are described in *research integrity* frameworks (which are increasingly binding on researchers in institutions and via funders' requirements), which include issues such as credit for contributions, manipulation of data or misappropriation of research funds.³⁵



Community consultation in Nairobi (partners from the TRUST project: UCLan, SASI, WITS, PHDA, three advisors)

Primary considerations in community engagement according to the four TRUST values

In the following table, the primary ethical considerations for community engagement in research are organised according to the four TRUST values. Of course, this table does not detail all considerations, because there will be others that are specific to individual scenarios. However, we provide here an overview of the main concerns that have been raised by the two over-researched communities that we have worked with on the TRUST project; sex workers from Nairobi and the San indigenous people from South Africa.³⁶ Hence, the considerations that we identify are based upon the real-world experiences of communities that have engaged with international researchers over a number of years.

³⁵ http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/h2020-ethics_code-of-conduct_en.pdf
<https://wcrif.org/guidance/singapore-statement>

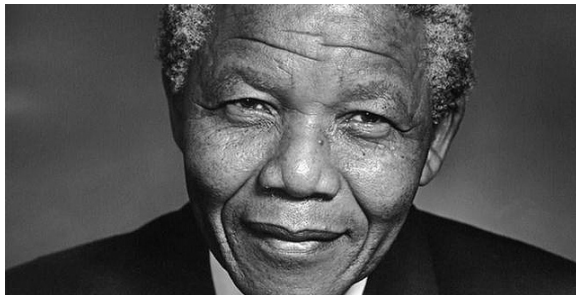
³⁶ The San have developed their own Code of Research Ethics based on these values available: <http://trust-project.eu/wp-content/uploads/2017/03/San-Code-of-RESEARCH-Ethics-Booklet-final.pdf>

Ethical considerations for community engagement in research

| Ensure fairness by: | Show respect for: |
|--|---|
| <p>Involving the community meaningfully in <i>all stages</i> of the study and its conceptualisation and implementation</p> <p>Engaging in full and frank discussions about the potential benefits and harms that the participants and the community might encounter</p> <p>Agreeing the most relevant types of benefits for the participants and communities (these are likely to include non-monetary benefits such as co-research opportunities, sharing of skills and research capacity, and roles for translators and research assistants)</p> <p>In health research, agreeing post-study access to successfully tested treatments or interventions</p> <p>Ensuring access to the findings of, for example, anthropological or social science research that can be beneficial for the community</p> <p>Discussing and agreeing the means for recognising and protecting traditional knowledge</p> <p>Helping to ensure compliance with ethical requirements and promises that have been made</p> | <p>Local/community research ethics codes and the need to comply with these</p> <p>The community's knowledge and its value to the research</p> <p>The community contribution to the research right from the planning stage</p> <p>The community as a whole and not just individuals; this is likely to involve leadership consultations prior to individual consent</p> <p>Community culture – including organisational structures, history, customs and norms, relationship with the environment, and sensitivities including previous unethical research</p> <p>Community preferences for engagement strategies</p> <p>The right to privacy, anonymity and confidentiality when requested</p> <p>The right to withhold personal/sensitive information</p> <p>The right of the community to refuse engagement/participation</p> <p>The community's entitlement to appropriate and accessible feedback and to be fully informed about the results of the study, including, if agreed, prior to publication</p> |
| Demonstrate care by: | Be honest through: |
| <p>Ensuring alignment of the research to local needs</p> | <p>Absolute transparency in all aspects of the engagement between the researchers and community representatives about the proposed study right from the start of discussions,</p> |

| | |
|---|--|
| <p>Paying due attention to the impact of the study and the study team upon the participants, their families, the local community and the environment</p> <p>Taking the time to ensure that the implications of the study have been fully understood by participants and the community</p> <p>Ensuring the community is properly resourced for participation</p> <p>Ensuring that the research is of high quality and worthwhile so that the efforts of the community are not wasted</p> | <p>including the funding situation, the purpose of the research, and any changes that might occur during the process</p> <p>Ongoing openness and clear channels of communication throughout the study and beyond, including a complaints procedure</p> <p>Disclosure of all details that might impact upon individuals or the community including potential harms and benefits</p> <p>The use of clear language and explanation of complex issues without being patronising</p> <p>Keeping any promises made, for example with regard to feedback of results</p> |
|---|--|

Guidance for effective community engagement in research



“Everything that is done for me without me is done against me”

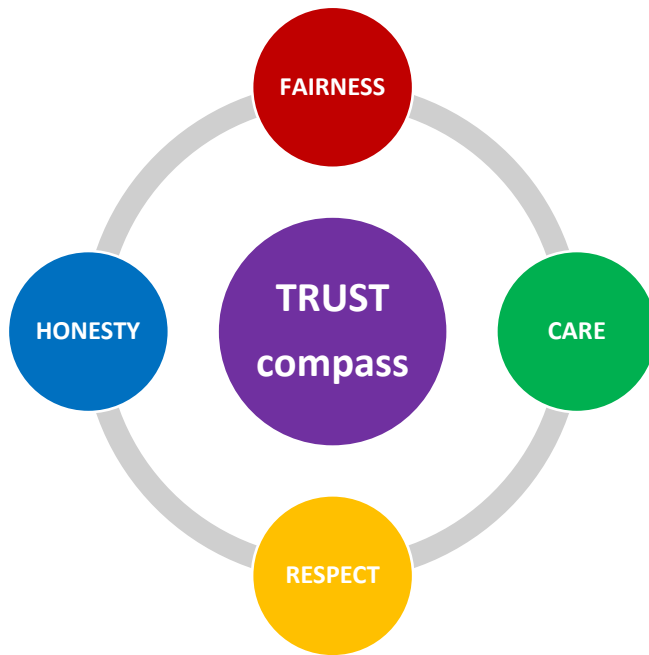
Nelson Mandela

37

In this section, we offer guidance for community engagement at each stage of a research study. Additionally, we show how the TRUST values can be used to guide community engagement at all points during the research process. It requires implementation of the ‘TRUST compass’ and reflexive awareness on the part of the researchers such that the researcher is able to consciously ‘stand back’ from their activities on a regular basis and ask whether their activities are aligned with the values.

³⁷ <https://www.flickr.com/photos/45582474@N02/9215883633>

The TRUST Compass



When used as a tool for contemplation at each step of the process, the TRUST compass will indicate whether the research is taking place within the limits of a trustworthy and ethical relationship.

When researchers apply the four TRUST values over the course of a research project, this creates a relationship of trust with the community.

The TRUST compass can be used on an on-going basis as a tool for ethical reflection but is particularly helpful at key stages during the research process. The whole research process is commonly comprised of five main phases, as indicated.

Guidance for community engagement at each of these five stages is described below, together with suggestions for how to implement the TRUST compass.

Research Stages



1. Formulation of research aims or question

Understanding the community

Researchers can find out a lot before they begin their activities. For instance, an oncology researcher can look at the occurrence of the disease in certain populations and identify any specific problems. Likewise, a social scientist or an ethnographer who work in substance abuse can familiarise themselves with existing research for given populations. Researchers should also try to find out about earlier research in the area which may have been problematic; this can help avoid pitfalls, aiming to transform and redistribute power, rather than further entrench unequal relationships. When supplementing academic knowledge about a potentially vulnerable community it is vital to consider the following:

- National and governmental structures, regulations and policies that may have bearing upon the research (for example, a specific bureau within the Ministry of Health, or Ministry of Agriculture, etc.).

- The structures/regulations involved with research undertaken in the community (for example, hospital, university, government department, local authority), and related ethics committees.
- Identification of local authorities, decision makers, and potential advocates or opponents of the research project (for example, political or religious orientations, advocacy groups).
- Social organisation, in particular leadership structures are important to identify but also, socio-economic status, economy and livelihoods, as well as community protocols.
- Identification of key persons who should be consulted/informed about the research project (traditional leaders, religious leaders, etc.).
- Identification of civil society organisations and advocacy groups who support the community.
- Identification of local researchers who have worked with the community before.
- Identification of international researchers who have worked with the community before to discover the history of past encounters.
- Identification of cultural and equality issues (such as customs, beliefs, habits, taboos) within the relevant region (national/local etc.) that may impact the community/research.

Respect for the social and political dynamics in a group is necessary for the design and implementation of an effective participatory strategy that will be inclusive of key stakeholders and can be sustained throughout the project. It is unwise to proceed in situations where there are serious tensions, for example, between competing leadership factions in a community.

The local trusted spokesperson

Of key importance, is the identification of trusted community spokespersons³⁸. As well as acting as translators, they can help interpret various signs and begin to build 'cultural bridges'. It is essential for international researchers to engage with trusted intermediaries who can assist in contacting key stakeholders, leaders and groups. This role can also fall to local researchers who have worked with the community before. An assessment should be made of the integrity and bona fides of such an intermediary, who should make his/her interest and involvement in the community clear.



Roger Chennells, Andries Steenkamp, Doris Schroeder; Spokesperson, San Leader, International Researcher for TRUST

³⁸ This is akin to the notion of a gatekeeper, contact person, or intermediary.

Understanding the community’s research needs

At first approach, it can be helpful to have a draft question to present to spokespersons, advocacy groups or local researchers for feedback. After discussion, a refined research question can then be taken to the community. At other times it may be more appropriate to co-create the research question from scratch. In both cases, it is important to consult first with the spokesperson and local researchers, and then with relevant community members. Individuals should only be approached once the researcher is sure that community structures for consultation have been respected.

It can be helpful to have a **draft research question** to present to spokespersons or local researchers for feedback.



At the community consultation stage, it is worth noting that communities are likely to be comprised of different sub-groups, and during this phase, one may find that different groups have a variety of priorities or viewpoints. Some persons may have a vested interest in preventing the research from taking place (for example, for financial reasons, or to protect their own interests), while other persons may have an interest in seeing it happen. This should be ascertained, and the reasons for their support or opposition understood. It is thus possible that the first engagement leads to a range of priority actions, corresponding to the different population groups. Additionally, the priorities established by the different groups may vary from those anticipated by the researchers (international and local) or even by the spokespersons or advocacy groups. In such cases, the solutions/questions that the researchers originally had in mind need to be left aside and further negotiations need to be undertaken to establish an appropriate course of action.

The researchers’ agendas should not be the primary driver. The needs of the local community must be given priority.



It is important to note that the researchers’ agendas should not be the primary driver in this type of inquiry. Rather, the needs of the local community must be given priority. However, to avoid disappointment and misunderstandings, the community should be fully informed of the researchers’ areas of expertise, the funding possibilities and the constraints of the proposed

project, which might not align fully with their research needs. It is also important at this stage to discuss the possible expectations that participants may have of the research. Research is often an alien concept to communities and the introduction of foreign, and seemingly well-resourced researchers, typically conveys an impression of potential benefits. It is important to be transparent at an early stage about the benefits that research can and cannot bring.

It is important to be transparent at an early stage about the benefits that research can and cannot bring.



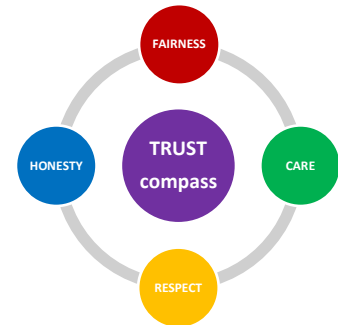
In some scenarios, researchers are approached by the community itself to instigate research. Community leaders or representatives may be aware that certain community problems (for example, the illegal harvesting of endangered plants with medical properties based on traditional knowledge, or the management of HIV in pregnancy) would benefit from scientific research. Or they might see an economic opportunity such as tourism which needs further research support. They, or a spokesperson, might be in a position to approach a research team for assistance. This is most likely if a

community member or a spokesperson are already part of the scientific or policy community themselves, thus emphasising the need for capacity building. Alternatively, earlier engagements might have enabled community members to have informal encounters with scientists, thus emphasising the benefit of longer-term partnerships.

Finally, in this initial phase, it is advisable to undertake a stakeholder analysis to identify and describe relevant stakeholders in the project. Each stakeholder may have different interests, concerns and capacities, and these need to be clearly understood in the process of identifying needs and setting objectives. This exercise is useful in managing the project, in communicating and disseminating project results, and in bridging research and advocacy.

Application of the TRUST compass

During the initial phase, when researchers are formulating their research aims or a research question, the TRUST compass can be applied through the following checklist to help ensure ethical considerations are addressed during community engagement. There may be other relevant questions, depending upon the circumstances, but these questions are a useful starting point.



| Fairness | Honesty |
|--|---|
| <ul style="list-style-type: none"> How are the community being meaningfully involved in discussions about the aims of the research, including why it is needed and who will benefit? | <ul style="list-style-type: none"> Have all background details been shared and discussed with the community, including the funding situation and the intentions of the researchers? What procedures will be used for two-way, open communication? What procedures are in place to ensure understanding of research issues without being patronising? What promises are being made to the community and can they be fulfilled? |
| Respect | Care |
| <ul style="list-style-type: none"> How are community preferences for engagement strategies being discussed and acted upon? Are the relevant community spokespersons or representatives being consulted? Is permission from community elders/leaders or representatives needed for this consultation? How are the research team familiarising themselves with local culture – including organisational structures, history, traditions, relationship with the environment, and sensitivities? | <ul style="list-style-type: none"> How are local needs and the potential for capacity building being taken into account in development of the aims? Is due attention being paid to the impact of the study and the study team upon the participants, their families, the local community and the environment? |

2. Designing the research project

Integral to meaningful collaboration is placing emphasis upon the research process rather than research outcomes. A commitment to process means that we must be prepared to take time to build relationships and expect the unexpected, for research processes are subject to human processes. ³⁹

To conduct research with fairness and honesty, the community as well as local researchers need to be included in the research design process, both effectively and transparently.

Inclusion through steering groups

The best way to ensure that a research project is relevant and meets the needs of a community is to involve them in the design of the research, its implementation and the monitoring of all activities. Ongoing communication with stakeholders is essential, as well as responsive action where needed. In some cases, the establishment of a joint steering group that is comprised of stakeholder representatives can be an effective way of ensuring joint management. Furthermore, a steering group can also provide oversight of the research project to help ensure initial agreements are respected or modified in the interests of all. The steering group can also advise the researcher(s) on practical issues such as dressing appropriately, the unspoken rules of a community, or how to address a traditional leader. The steering group will need to be supported (financially and possibly in terms of mentoring and capacity building) by the project, and should also involve local researchers whenever possible.

The best way to ensure that a research project is relevant and meets the needs of a community is to **involve them in the design of the research.**



First discussion of TRUST proposal with San leaders prior to application to EU in !Khwa ttu, South Africa

The constitution of the steering group will vary according to the context. Be careful not to impose forms of organisation that are foreign to the local population as this can lead to lack of ownership, and hinder the integration of committees in the population. For example, well-intentioned offers to pay attendance allowances/fees for participation can lead to problems in low-income settings, exacerbating economic disparities. Where possible, it can be helpful to work with existing committees or collective bodies (village council, local organizations, etc.) who have established practices, rather than trying to create a new committee. However, in communities

³⁹ Summary report: Conscious Research Seminar. Knowledge, process and practice, University of Cape Town, 16 November 2017 p2

where certain voices (women, for example) are underrepresented, or are not permitted to be part of any representative committee, other ways must be found to ensure access and elicit their views about the study.

Gender and inclusion issues⁴⁰

In some communities, traditional gender roles may conflict strongly with the expectations and aspirations of the researchers, their institutions and funders for the full and active participation of women in all aspects of the research process. The resulting challenges need to be addressed in relation to the spirit of gender justice, international guidelines, and the commitments to women's rights and equality in the countries where the research is based, but in the context of respect for the specific communities where the research takes place. Attention should be paid to both gender and age differences; depending on local customs for example, it may be necessary to divide groups into male and female, or young and old, as customary rules may preclude one group from expressing itself in the company of the other.

When wondering how to approach such issues, one might consider researchers' reflections about their assumptions of observing 'gender inequality', as a manifestation of cultural difference.⁴¹ In response to questions about these issues, San leader Victoria Haraseb suggested that women ought to be asked about it; this means that the appropriate research design strategy is to engage with the women in the community and not impose external or imperialistic understandings.⁴² Community engagement may reveal that many of these rights and issues are already under discussion in the political agendas of, for example, indigenous peoples, or communities within communities, which provides opportunities for researcher engagement.⁴³

Ethics approval

When seeking ethics approval for research with vulnerable communities it is important to distinguish between the need to obtain general prior informed consent for participating in the research project, and, where appropriate, obtaining specific consent for sensitive areas such as the use of images (whether stills or video) of research participants. It is also important to recognise that while ethics approval processes are typically one-off events, research itself is iterative, and the researcher is often faced with ongoing decisions that require continual review (and potentially referral back to the ethics committee if research protocols need to be amended). Obtaining ethics approval

Obtaining ethics approval for a study is not a substitute for a thorough community involvement process.



⁴⁰ Most research projects involve human research participants; others may include research about plants, animals or the wider environment; we focus here on research with human participants.

⁴¹ Simonelli J, Earle D 2003 Meeting resistance:Autonomy, development and 'informed permission' in Chiapas, Mexico. *Qual Inq* 9 (1):74-89.

⁴² Cook Lucas, J, Alvarez Castillo, F, Fair for Women? A Gender Analysis of Benefit Sharing, in Schroeder and Cook Lucas (eds)Benefit Sharing, from Biodiversity to Human genetics, Springer 2013.

⁴³ For a situated discussion of guiding principles, strategies and recommendations around gender in community research with vulnerable populations, such as membership of decision-making bodies, separate bodies and consultations, see:

http://clonk.uclan.ac.uk/16030/1/CQ_Vulnerability_Gender_Castillos_Lucas_1.pdf

for a study is therefore not a substitute for a thorough community involvement process.

It is recommended by many ‘best-practice’ guidelines,^{44,45,46} as well as being a requirement of many research funders,⁴⁷ that protocols are submitted for approval to at least two ethics committees; one from the “home” country of the research institution and one from each “host” country, which will review the project independently, albeit in a complementary fashion. In practice, it is advisable that the researcher first obtains the opinion of the “home” ethics committee, in order to be sure that the ethical standards of his/her own country or institution are respected, before submitting the project to the “host” country’s ethics committee. The “home” ethics committee’s approval should then be conditional on “host” committee approval. In general, in case of diverging opinion between the two committees over specific issues, the “host” country’s ethics committee’s opinion is expected to prevail.⁴⁸

Any local guidelines or requirements (including for example, indigenous peoples’ codes) must also be respected and the appropriate processes followed before the research can be considered to have necessary ethical approval.

Community representatives and advocacy groups are entitled to request evidence of appropriate ethical approval at each stage, and to use the prescribed query or complaints procedures for further information if they wish.

Recruitment

The selection and recruitment of research participants is one of the most sensitive steps in the project cycle and must be handled carefully. Hence, this process should be participatory. As a first step, the community should be involved in defining the selection criteria. This can also help the community to understand the selection process and risk-benefit ratio. In some contexts, the targeting of specific individuals as participants is not well-understood and this can be socially unacceptable, particularly where risks and benefits are not equally distributed. The selection process can have major impacts on social relationships and it can exacerbate both jealousy and discrimination. If the researcher uses random sampling, for example, it is important to explain to those who are not selected, why this is the case. This will help to avoid unbalancing social

The selection process can have major impacts on social relationships and it can exacerbate discrimination.



⁴⁴ Nuffield Council on Bioethics, The ethics of research related to healthcare in developing countries, 2002 paras 8.22-8.25 <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Ethics-of-research-related-to-healthcare-in-developing-countries-1.pdf>

⁴⁵ “Good Clinical Practice in developing countries: applying recommendations. F. Bompard, F. Hirsch, P-H Bertoye, M. Vray. *Therapie* 2008 ; 63(2) 77-88.”

⁴⁶ Parliamentary Office of Science and Technology, Postnote Research Ethics in Developing Countries, April 2008. <http://www.parliament.uk/documents/post/postpn304.pdf>

⁴⁷ The Wellcome Trust, Research involving people in low- and middle-income countries guidance notes. <https://wellcome.ac.uk/funding/managing-grant/guidance-notes-research-involving-people-low-and-middle-income-countries>

⁴⁸ Note that this relates to specific issues such as appropriate consent strategies, or the need for translated written materials etc. It does not open the door for “ethics dumping”, where lower ethical standards are deemed to be acceptable in the global South. <https://link.springer.com/book/10.1007%2F978-3-319-64731-9>

relations. Participatory selection processes aim to ensure that the process is transparent and culturally acceptable.

Many projects, such as those in health and nutrition, must target specific groups, defined by physical or behavioural criteria. These criteria will be determined by fixed health protocols, but they need to be explained fully to the communities and be reviewed and discussed with them, with the help of advocacy groups when relevant. In some cases, achieving a balance between a respect for social norms and research excellence can be complex. For instance, a study of nutritional assistance for pregnant women might come into conflict with local norms in contexts where women and girls eat after male members of the family, and/or where food rations are shared amongst all the members' family.

Consent

The timing of the consent process should be carefully considered, especially in a collaborative or co-designed project; in the early stages the exact nature of a study may not be clear enough to identify exactly what participants might eventually be consenting to.

Every potential participant should always be given the option to refuse (or, more respectfully, decline) participation, with no questions asked or any repercussions. They should also be made aware that if they do decide to take part, they can withdraw from the study at any time. Researchers must make concerted efforts to ensure that all research participants fully understand the burdens and benefits of a research project and are in a position to provide their fully informed consent. This may mean that extra care is taken to ensure information is provided in a manner that is accurate yet culturally sensitive and adapted to the context. Community engagement can help to identify the type of information that is needed and how it is best provided.⁴⁹

Indigenous peoples may speak their indigenous languages only, and this may not be a written language. This comes with particular challenges for both sides, and providing a written consent form is not sufficient in these circumstances. When working with any communities who do not use written language, the consent process needs special attention in order to make sure that the participants receive all the relevant information needed to make an informed choice about their participation.



Interpretation into local languages

Cultural background might additionally mean that the participants have no prior

⁴⁹ H3Africa Working Group on Ethics and Regulatory Issues for the Human Heredity and Health (H3Africa) Consortium, H3Africa Guidelines for Community Engagement, 2014 http://www.health.uct.ac.za/sites/default/files/image_tool/images/116/documents/research/H3Africa%20CE%20Guidelines_Final.pdf

knowledge about the research topic and that certain terminology does not exist in their indigenous language. To overcome such communication challenges, researchers have historically used strategies such as storytelling, performance or theatre, and more recently have looked into using visual tools, such as creating small video clips where a community member explains the research and the consent process in their mother tongue.

Researchers should pay attention to community dynamics when seeking consent. Consent must always be obtained from each individual, but there may be another level of consent at the community level, which needs to be considered. This is particularly salient if the researcher comes from “Western countries where individual autonomy is more highly regarded”.⁵⁰ In addition, in some settings the permission of for example, a male family member may be required for a woman to participate (or not), although this must never override her own wishes.⁵¹

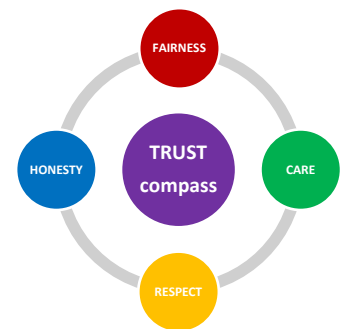
Time frames

Working with communities can be a slow process and time is needed to build trust with participants. Often this is not accounted for within the time-frames given by funders, study curricula or similar, and the impact of this should be considered.

It is also important to keep in mind the time taken from participants. This may include factors such as travel time or preparation time, as well as actual participation. Community input on the proposed time-frame is necessary to ensure that it is both realistic and acceptable. Plans may be affected by all types of issues that are unforeseen by the researchers such as the climate and seasonal availability of participants. For example, it could have serious implications for farm workers to participate during harvesting time. It may be useful to co-develop a calendar of the year to see when participants are most likely to be busy, or when the weather might be unsuitable for research.

Application of the TRUST compass

During the design phase, when researchers are working with a community to plan their investigations, the TRUST compass can be applied through the following checklist to help ensure ethical considerations are addressed during community engagement. There may be other relevant questions, depending upon the circumstances, but these questions are a useful starting point.



| Fairness | Honesty |
|---|---|
| <ul style="list-style-type: none"> How are the community involved in the planning and design of the study? | <ul style="list-style-type: none"> How is absolute transparency in all aspects of the engagement and planning being ensured? |

⁵⁰ Oonagh Corrigan 2003 Empty ethics: the problem with informed consent. <http://onlinelibrary.wiley.com/doi/10.1046/j.1467-9566.2003.00369.x/full>.

⁵¹ Cook Lucas, J, Alvarez Castillo, F, Fair for Women? A Gender Analysis of Benefit Sharing, in Schroeder and Cook Lucas (eds) Benefit Sharing, from Biodiversity to Human genetics, Springer 2013.

| | |
|---|---|
| <ul style="list-style-type: none"> • Are the potential benefits and harms for the participants and the community being discussed fully and frankly? • Have the most relevant types of benefits for the participants and communities been discussed and agreed? • In health research, has post-study access to successfully tested treatments or interventions been agreed? • Where relevant, have means for recognising and protecting traditional knowledge been agreed? | <ul style="list-style-type: none"> • Are procedures for open, two-way communication in place? • Have all details that might impact upon individuals or the community been disclosed? • Have requirements for an accessible and user-friendly complaints mechanism been discussed and agreed? • What promises are being made to the local community in the design of the study and can they be fulfilled? |
| Respect | Care |
| <ul style="list-style-type: none"> • Are the research team complying with local/community ethics codes? • How is community knowledge being respected and integrated into the design? • Are the relevant members of the community, as identified by the community itself, involved in the design? • How is community culture and tradition being respected in the design of the study? • Have the relevant persons in the community given permission/approval for the study design? | <ul style="list-style-type: none"> • How are local needs being taken into account in the design of the study? • Is due attention being paid to the impact of the study and the study team upon the participants, their families, the local community and the environment? • What measures are in place to aid communication and understanding (such as translators, use of clear and non-technical language etc.)? • Have the resource implications for the local community that are associated with this design been identified? • What measures are in place to ensure that the research is high quality and worthwhile so that the efforts of the community are not wasted? |

3. Research implementation

Community involvement in the operational research project

Where possible, it is important to involve members of the local community in undertaking the research. This may be in simple operational practical or administrative capacities, but where appropriately qualified or experienced candidates are available, and/or where appropriate training can be provided, it should also include more complex tasks such as data collection, and/or analysis and write up of the project results, with support from

Services such as translation should be remunerated fairly.



experienced researchers.⁵² Such capacity building can help to ensure long-term benefits to the community beyond the end of the study. Importantly, services such as translation and facilitation should be remunerated at a fair local rate.

Active participation can also be ensured via the research approach or choice of methods employed. By using Participatory Action Research⁵³, for example, community members are given a voice and participation is democratized.

Ongoing two-way consultation, monitoring and feedback

It is vital that there are open lines of communication between researchers and the community *throughout* the research. These should include an agreed complaints/feedback procedure, but can also include other formal structures such as a steering group, as well as informal means, so that the community members feel free and comfortable enough to make comments or raise concerns. Equally, it is essential that the researchers make an effort to update the community on research progress and discuss any changes, particularly changes which require further ethical approval.

While the research study is ongoing, regular meetings can be held by the steering group to monitor and evaluate progress. Additionally, it can be helpful to organise regular meetings with the community to provide updates and seek feedback. Such meetings offer a community the space to speak, to seek answers to questions about the research and for researchers to address their concerns. Risks that were pre-identified at the beginning of the project can be regularly reviewed and discussed with the community to help find solutions or make modifications to the research protocol where necessary (subject to ethical approval).

It is vital that there are open lines of communication between researchers and the community *throughout* the research.



Payment and gifts

When consulting with communities or recruiting participants, undue incentives should be avoided. While it is important to respect benefit sharing agreements that have already been established, payment or gifts of any form to communities or research participants, other than re-imbursment of reasonable expenses (i.e childcare costs or travel expenses), are always problematic, carrying the potential to be seen as exerting some form of unwarranted or undue influence on decision-making. The provision of a good meal, a cup of tea, or refreshments for taking part in a group activity can be justified, but providing potential research participants, either collectively or individually, with other forms of payments or gifts is justifiably regarded as contrary to ethical norms or best practice, and needs careful consideration. It is important to remember that the more impoverished a community is, the greater the risk that even a small financial payment can be incentivizing ('coercive' in the sense that it undermines free consent).

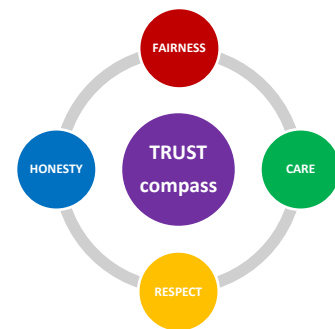
⁵² Most if not all projects involve local people, but using "community" people with no specific training or diploma will not be possible for many medical research projects, which need to be managed by people professionally trained in Good Clinical Practice. Also, the issue of confidentiality of the data can be challenging.

⁵³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566051/>

Any proposed payments or gifts to communities or research participants must be declared to the ethics committees involved in reviewing the proposal, and are therefore subject to ethical approval. This mechanism should remove any conflict over this question for the individual researchers, although once in the field this can be challenging. The local, “host” ethics committee should be a good resource to help determine what are “fair” or appropriate payments or gifts to communities and participants. Community or local codes may also have application to these issues. However, undue inducement considerations should not influence situations of immediate and pressing needs. For instance, if the field worker is the only person with transport in a community and a member needs urgent hospitalization, the request cannot be rejected based on claims of undue inducement. Common decency should not be switched off when on research projects.

Application of the TRUST compass

During the implementation phase, when researchers are working with a community to undertake their investigation, the TRUST compass can be applied through the following checklist to help ensure ethical considerations are addressed during community engagement. There may be other relevant questions, depending upon the circumstances, but these questions are a useful starting point.



| | |
|--|--|
| Fairness | Honesty |
| <ul style="list-style-type: none"> • How are the local community engaged in the ongoing implementation of the research? • Are local researchers and other members of the community taking active roles in the implementation? • Have measures for ensuring ethical compliance been discussed with the community and put in place? | <ul style="list-style-type: none"> • How are lines of communication working? Is there clear and transparent, two-way communication between the research team and local community? • How are the community being informed about developments, or of any changes that occur during the research process? • How is the complaints system functioning? Does it need to be amended in any way? |
| Respect | Care |
| <ul style="list-style-type: none"> • Are researchers taking steps to ensure all activities are respectful of local culture and traditions? • Has both individual and community consent (where appropriate) been granted? • What measures are in place to respect rights to privacy, anonymity and confidentiality? • Are the participants and community fully aware of their rights to withhold personal/sensitive information and to refuse/decline engagement/participation? | <ul style="list-style-type: none"> • Have the researchers taken the time and necessary steps to ensure that the implications of the study have been fully understood by participants and the community? • Are researchers paying attention to the impact of the study and the study team upon the participants, their families, the local community and the environment? • Is the community being properly resourced for participation? |

4. Research results

Findings can be enriched when members of the community are consulted and engaged during the analysis process and the interpretation of results. For some studies, the sharing of results with the research participants or the community can reveal aspects that are hidden to the researchers (for example, an understanding of why or how something happens).

Feedback of results

Research findings should be used with respect and care. Research participants may have invested a lot of thought, and sometimes time and effort, into a research study. However, unlike the researcher, this is not their livelihood and there is no immediate gain. Hence, researchers must ensure that the results and implications are fed back appropriately and promptly. Steering groups and spokespersons can help to decide how results should be disseminated within communities, and this may take place in the form of public events. Where written feedback is provided, this may also need to be translated and/or explained in lay terms.

Sensitive or controversial results

Research findings are sometimes highly sensitive, with the potential to alter the dynamics both within communities, and between communities and external agencies. This is especially the case for social and policy research, where the focus might be upon understanding conflicts or power dynamics, or the impacts of a policy intervention.

In some cases, research results regarded as stigmatizing and discriminatory by the community, have been published despite their attempts to protest. For example, in genomic research conducted by Schuster *et al.*⁵⁴, the San attempted to register their disapproval at the fact that the research had not been approved by their leaders, and prior to publication they had not had an opportunity to examine the research results, which contained numerous problematic findings for them. The authors ignored the complaints, the publication went ahead, and it was only years later that the San were able to develop their own ethical code to prevent such harmful research from being undertaken or published in the future.⁵⁵ Where a community does not have both an agreed code of research ethics and the capacity to protect their own interests, then maintenance of ethical research practices such as the double ethics review process described above would help to prevent the occurrence of such harm to the community.

It is of the utmost importance that research results are discussed with the community before these are publicly released.



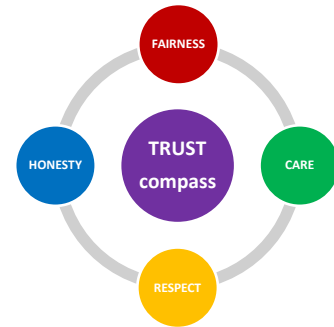
It is therefore of the utmost importance that research results are discussed with the community, including an agreed plan for their wider dissemination, before these are publicly released.

⁵⁴ Schuster SC, Miller W, Ratan A et al, 2010, Complete Khoisan and Bantu genomes from southern Africa. *Nature* 463:943 – 947. <http://dx.doi.org/10.1038/nature08795>

⁵⁵ Chennells R, Steenkamp A, International Genomic Research Involving the San people, in Schroeder et al Ethics Dumping, Case Studies from North-South Research Collaborations, SpringerOpen 2017.

Application of the TRUST compass

Once the empirical component of the study is completed and researchers are working on the findings, the TRUST compass can be applied through the following checklist to help ensure ethical considerations are addressed during community engagement. There may be other relevant questions, depending upon the circumstances, but these questions are a useful starting point.



| Fairness | Honesty |
|---|---|
| <ul style="list-style-type: none"> • How are members of the local community involved in analysis and interpretation of the results? • What measures are in place to ensure access to findings that might be beneficial for the community? • Are appropriate steps being taken to recognise and protect traditional knowledge contributions? | <ul style="list-style-type: none"> • Have promises that were made about access to the results been fulfilled? • Have all findings been disclosed in an honest manner? |
| Respect | Care |
| <ul style="list-style-type: none"> • Have the community been given an opportunity to review the results and implications of the study prior to publication? • Has the community's knowledge and contribution been fully acknowledged in the results? • Has community culture and tradition been taken into consideration in interpretation of the results? • Have rights to privacy, anonymity and confidentiality in reporting been respected? | <ul style="list-style-type: none"> • What measures are in place to ensure that the findings and implications of the study are accessible and fully understood by participants and the community? |

5. Evaluation

It may seem as though the publication of research results and feedback to the community represents the end of the research cycle. However, to improve the process for further research involving this or other communities, it is helpful to evaluate the study, and in particular in the context of this report, the community involvement elements. This may also help build long-term, mutually beneficial partnerships.

Evaluation of the research process

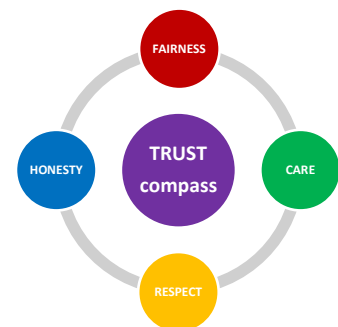
Community feedback on their experience of the research process can be a valuable exercise for both the researchers and the community members. For the community, it may help them to reflect upon what worked well for them, and what did not. This can be used to inform and adjust any future dealings with researchers. For the researchers, it is vital that they listen and learn from the community perspective on the research process. For instance, there may have been positive or negative impacts upon the community that were unforeseen and not mentioned over the course of the project, but which could be addressed in future collaborations. As has been stated on numerous occasions by indigenous communities, their preference for the development and maintenance of a relationship of trust with the research institution underlies all ethical requirements. Evaluation of research results is the kind of engagement calculated to deepen this trust.

Evaluation of the research impact

The ultimate aim of a research study is beneficial impact; research without any perceived benefits is unethical. An ideal research study will have positive impact in an area where needs and opportunities had previously been identified by and with the relevant community. If this were not envisaged, the use of time and resources on both sides, as well as the research burdens, would not be justifiable. Even where impact is difficult to assess, post-research evaluation is vital to assess whether the research was responsive to the needs of the community, and that any benefits from the research have been made available to those communities.

Application of the TRUST compass

Beyond the end of the study, the TRUST compass can be applied through the following checklist to help ensure ethical considerations are addressed during the evaluation of the project with the community. There may be other relevant questions, depending upon the circumstances, but these questions are a useful starting point.



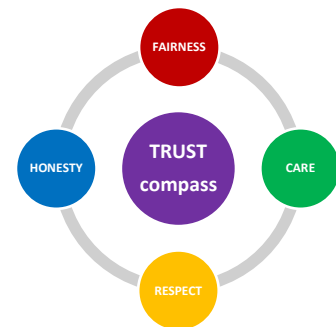
| Fairness | Honesty |
|--|--|
| Have the agreed benefits for participation been realised? | Have all promises to the community been fulfilled? |
| In health research, is the agreed post-study access to successfully tested treatments or interventions being made available? | How have complaints been managed? Are there lessons to be learned and shared? |
| How have the community been involved in an evaluation of the research findings? | Have implications that might impact upon individuals or the community including potential harms and benefits been disclosed? |
| How have the community been involved in an evaluation of the research process? | |

| | |
|--|--|
| Do the community believe that they have benefitted from the research? | |
| Respect | Care |
| <p>Are there mechanisms in place to feedback news about broader impacts of the research?</p> <p>Has the contribution of members of the local community been fully accredited?</p> <p>Has the community's knowledge and its value to the research been fully accredited?</p> <p>Do the community believe that their local culture and tradition has been respected?</p> | <p>Do the community believe that the research met local needs?</p> <p>Do the community believe that researchers paid due attention to the impact of the study and the study team upon the participants, their families, the local community and the environment?</p> <p>Was the resulting project of high quality and worthwhile so that the efforts of the community were not wasted?</p> |

Conclusion

Community engagement is an effort, which can bring many benefits. Amongst these are:

- for the researchers, a much better understanding of a local situation than helicopter research would allow and access to knowledge and voices, which will enhance research.
- for the community – assistance with research questions, which can improve local well-being and international engagement and possibly capacity-building.



Our main advice is to build long-term, mutually beneficial relationships based on the values of fairness, respect, care and honesty, to apply before, during and after research studies.



UCLan fieldworker in community consultation in Botswana