



6.2 Pictorial Project Report 1

Doris Schroeder and TRUST Consortium

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Executive Summary

Target 9.5 of the 2030 Agenda for Sustainable Development aims to:

Enhance scientific research, upgrade the technological capabilities of industrial sectors in all countries, in particular developing countries, including, by 2030, encouraging innovation and substantially increasing the number of research and development workers per 1 million people and public and private research and development spending.¹

Contributing altruistically to meaningful research is a service to humanity. However, in the context of North-South collaborations in research, asking for altruism from research participants is misplaced.² The TRUST team believe that North-South collaborations in research should be guided by four core values: fairness, respect, care and honesty.³



An overview of our activities can be obtained from our engagement deliverable,⁴ from our website,⁵ and from our funder's website, where we were singled out as a success story⁶, or, for one of our biggest achievements to date, from the international press.⁷

We would like to use this pictorial report to go beyond a mere activity report, which would duplicate work already done (e.g. engagement report), as follows.



Partners and advisors from around the world who agreed the four TRUST values have contributed proverbs and quotes from their countries to show how deeply engrained these values are in their lives locally.

(All images were taken by TRUST colleagues, unless otherwise indicated).

¹ <https://sustainabledevelopment.un.org/post2015/transformingourworld>.

² Doris Schroeder (2008) Double Standards and Benefit Sharing, Monash Bioethics Review, Vol. 27(4)45-51.

³ Please see the appendix for explanations on the four values.

⁴ http://trust-project.eu/wp-content/uploads/2016/03/TRUST-1st-Engagement-Report_Final.pdf

⁵ <http://trust-project.eu/>

⁶ http://www.sisnetwork.eu/media/sisnet/Success_Story_TRUST.pdf

⁷ <http://trust-project.eu/san-code-of-research-ethics/>

Fairness



Contribution from South African researcher and research participant



If you are neutral in situations of injustice, you have chosen the side of the oppressor. If an elephant has its foot on the tail of a mouse and you say that you are neutral, the mouse will not appreciate your neutrality.

Desmond Tutu (1931)



First justice, then charity.

German proverb


Erst gerecht, dann wohltätig.

In youth, we believe that
the least we can expect
from others is justice;
when old, we know that it
is the best.

Marie Freifrau von Ebner-Eschenbach
(1830-1916)

In der Jugend meinen wir, das Geringste, das die Menschen
uns gewähren können, sei Gerechtigkeit. Im Alter erfahren
wir, daß es das Höchste ist.

Contribution from German researcher and research participant

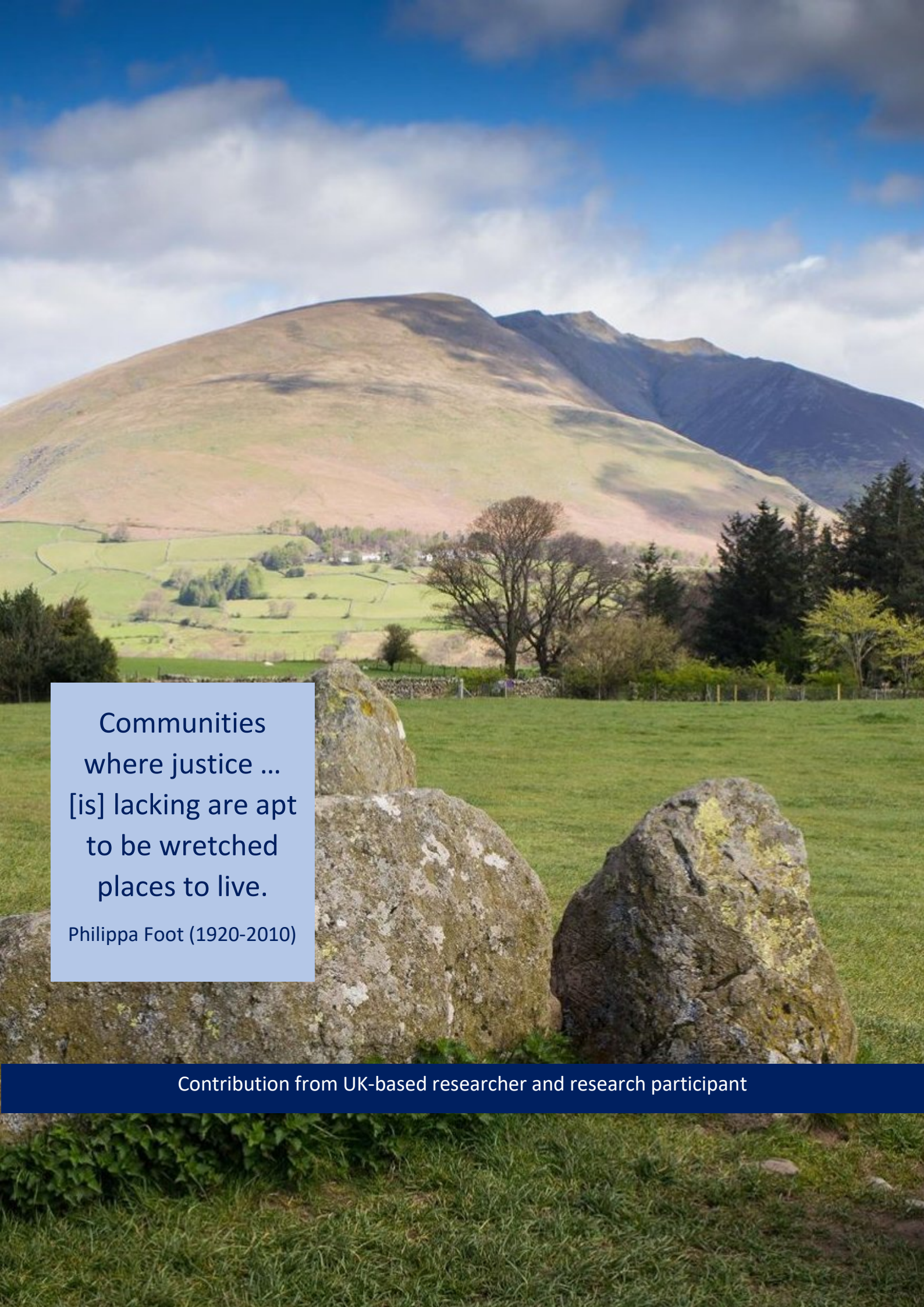


Our only task is to be just.
This means, we have to
point out and resolve
injustice without
establishing new creeds.

Ludwig Wittgenstein (1889-1951)

Unsere Aufgabe ist es nur, gerecht zu sein. D.h., wir haben
nur die Ungerechtigkeiten ... aufzuzeigen und zu loesen,
aber nicht neue... Glaubensbekenntnisse aufzustellen.

Contribution from Austrian researcher and research participant



Communities
where justice ...
[is] lacking are apt
to be wretched
places to live.

Philippa Foot (1920-2010)

Contribution from UK-based researcher and research participant

Those who are well off would be better off if those who are worse off were better off; but this doesn't work without making those worse off who are better off, that's why nothing much happens to make life better for those who are worse off; and that's why the well off are not better off.

Mani Matter (1936-1972)

dene, was guet geit / giengs besser / giengs dene besser / was weniger guet geit / was aber nid geit / ohne dass's dene / weniger guet geit / was guet geit/drum geit weni / für dass es dene / besser geit / was weniger guet geit / und drum geits ou / dene nid besser / was guet geit

(Free images, photo by David Chambers)

Injustice anywhere is a
threat to justice
everywhere.

Martin Luther King (1929-1968)




Justice in the life and
conduct of the State is
possible only as first it
resides in the hearts and
souls of the citizens.

Plato (428-348 BC)

Η δικαιοσύνη στη ζωή και τη συμπεριφορά του κράτους
είναι δυνατή μόνο ως πρώτη που κατοικεί στις καρδιές και
τις ψυχές των πολιτών.

Photo freeimages B Boy






Until the lion learns
how to write every
story will glorify the
hunter.

African proverb

Respect



Do not belittle what
you did not
cultivate.

Ugandan proverb (Luganda)

Kyootaalima tokinyooma

Contribution from Ugandan researcher and research participant

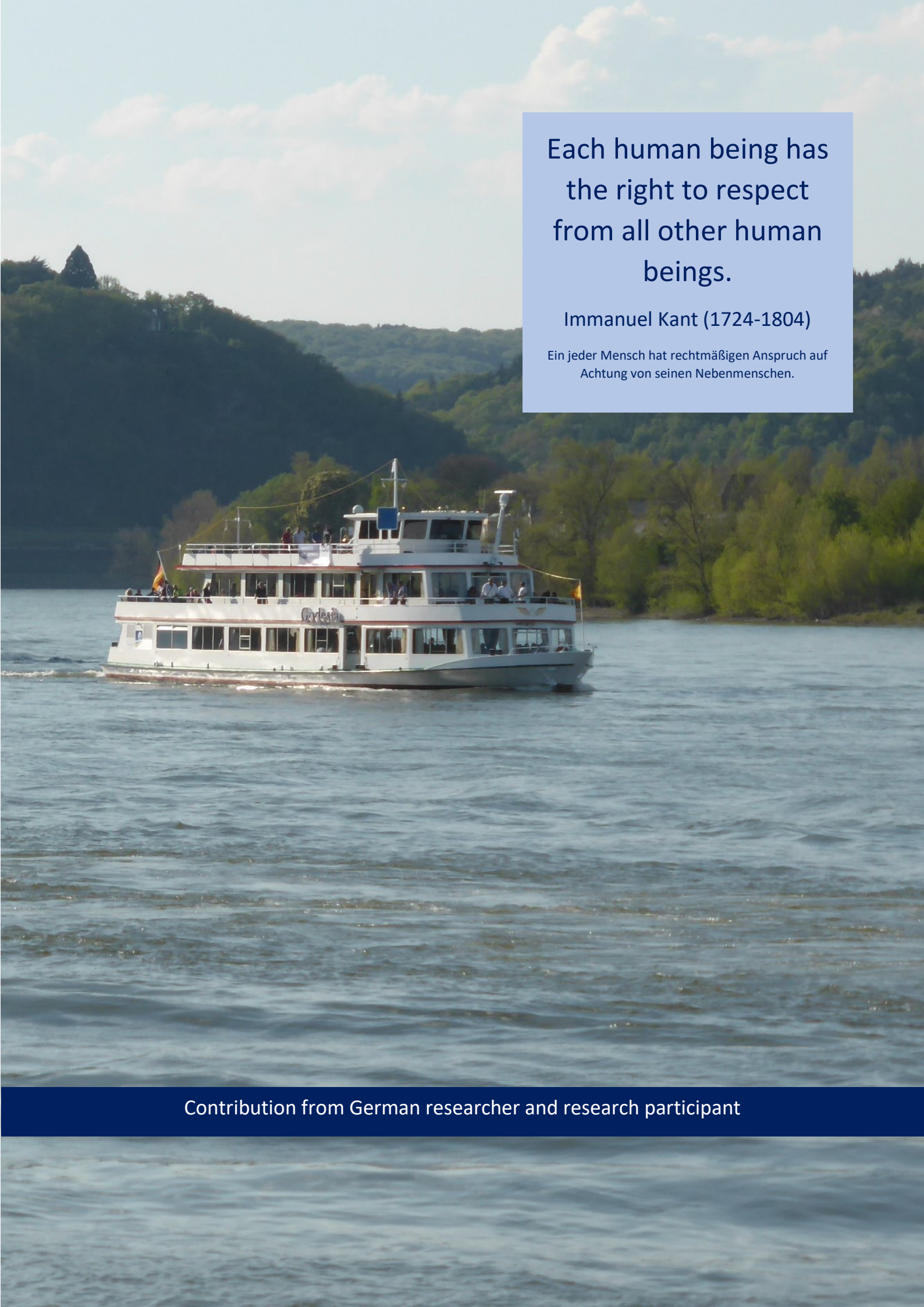
A wide-angle photograph of a dry, open landscape. In the foreground, a wide, reddish-brown dirt road with deep tire tracks leads from the bottom left towards the center. The ground is sandy and sparsely covered with dry grass. Several acacia-like trees are scattered across the landscape, with a larger one on the left and a few smaller ones further back. The horizon is flat and distant under a clear, bright blue sky.

Contribution from San community and research participant, South Africa

In order to show respect
for San, researchers should
enter via the front door,
and not via the window.

Andries Steenkamp (1960-2016)

Om die San te respekteer, moet navorsers by ons voordeur
inkom, en nie deur die venster nie.



Each human being has
the right to respect
from all other human
beings.

Immanuel Kant (1724-1804)

Ein jeder Mensch hat rechtmäßigen Anspruch auf
Achtung von seinen Nebenmenschen.

Contribution from German researcher and research participant

Contribution from Indian researcher and research participant



Relationships are based
on four principles:
respect, understanding,
acceptance and
appreciation.

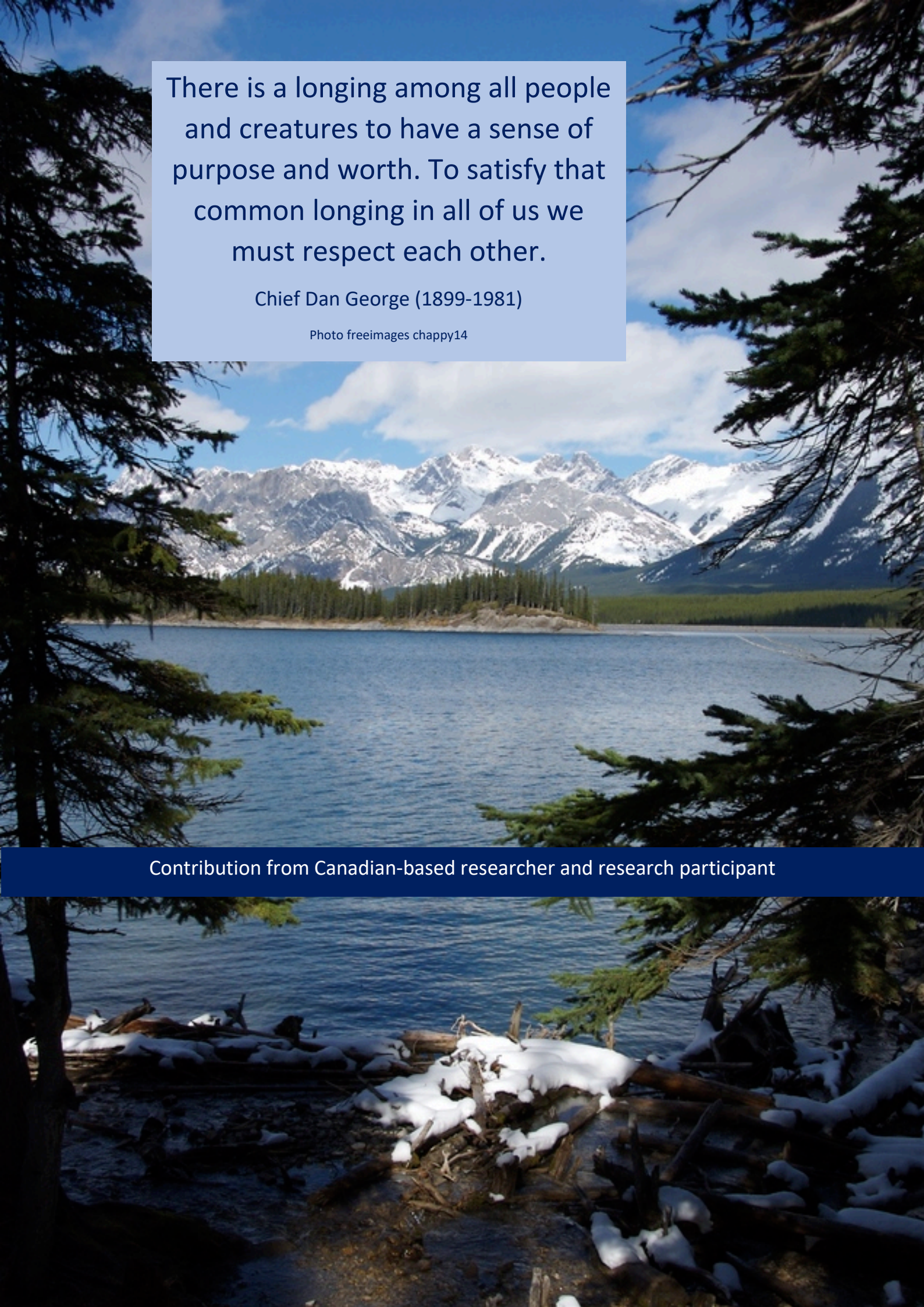
Mahatma Gandhi (1869-1948)



I do not choose nor do I
segregate, for I don't
know who will attend
my funeral.

Kenyan proverb about respect

Sichagui sibagui atayenizika simjui



There is a longing among all people
and creatures to have a sense of
purpose and worth. To satisfy that
common longing in all of us we
must respect each other.

Chief Dan George (1899-1981)

Photo freeimages chappy14

Contribution from Canadian-based researcher and research participant

Among individuals, as
among nations, respect
for the rights of others
is peace.


BP Juárez García (1806 –1872)

Entre los individuos, como entre las naciones, el
respeto al derecho ajeno es la paz.

Photo freeimages Mira Pavlakovic





A photograph of a Parisian street at dusk. In the foreground, a cafe with a yellow awning has outdoor seating with red chairs and white tables. A tall, curved building with a dome is visible in the background. The sky is a deep blue, and streetlights are on. A semi-transparent blue box with white text is overlaid on the right side of the image.

The one who is spared
suffering must feel
called to relieve the
suffering of others.

Albert Schweitzer (1875-1965)

Celui à qui la souffrance est épargnée doit se sentir
appelé à soulager celle des autres.

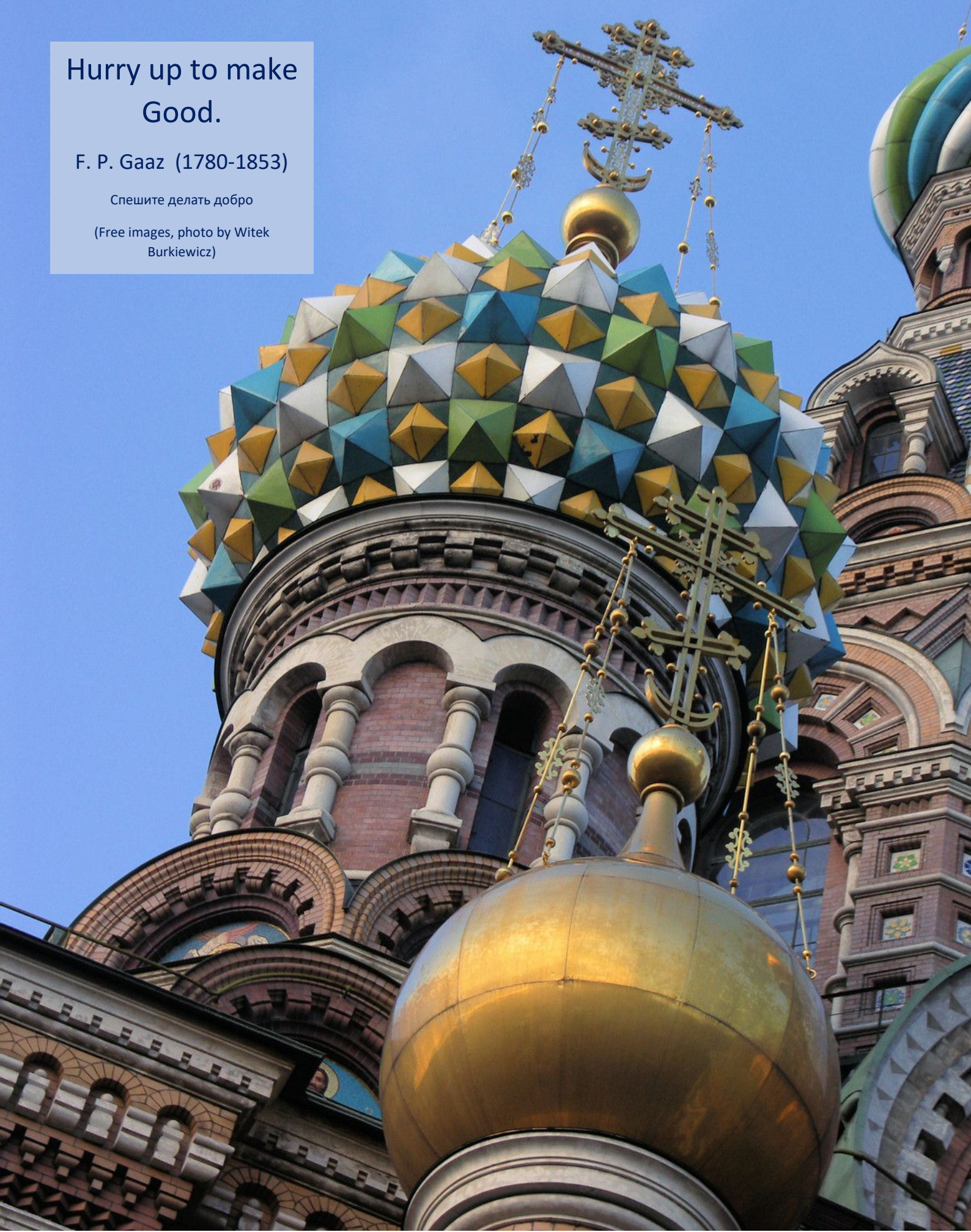
Contribution from French researcher and research participant

Hurry up to make
Good.

F. P. Gaaz (1780-1853)

Спешите делать добро

(Free images, photo by Witek
Burkiewicz)

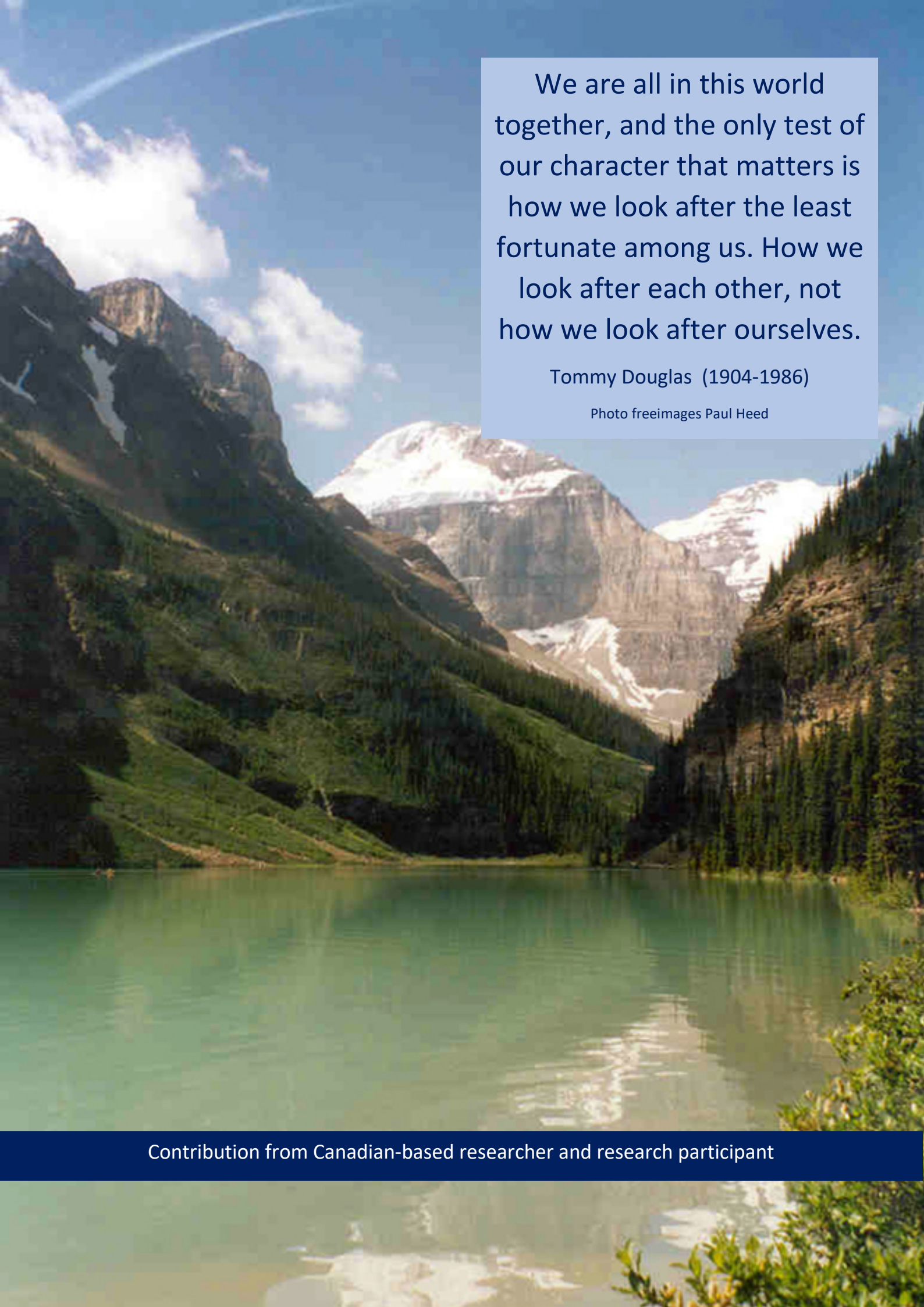


Kind words can be short
and easy to speak, but
their echoes are truly
endless.

Mother Theresa (1910-1997)

Albanian-Indian





We are all in this world together, and the only test of our character that matters is how we look after the least fortunate among us. How we look after each other, not how we look after ourselves.

Tommy Douglas (1904-1986)

Photo freeimages Paul Heed

Contribution from Canadian-based researcher and research participant



Contribution from Australian-based researcher and research participant

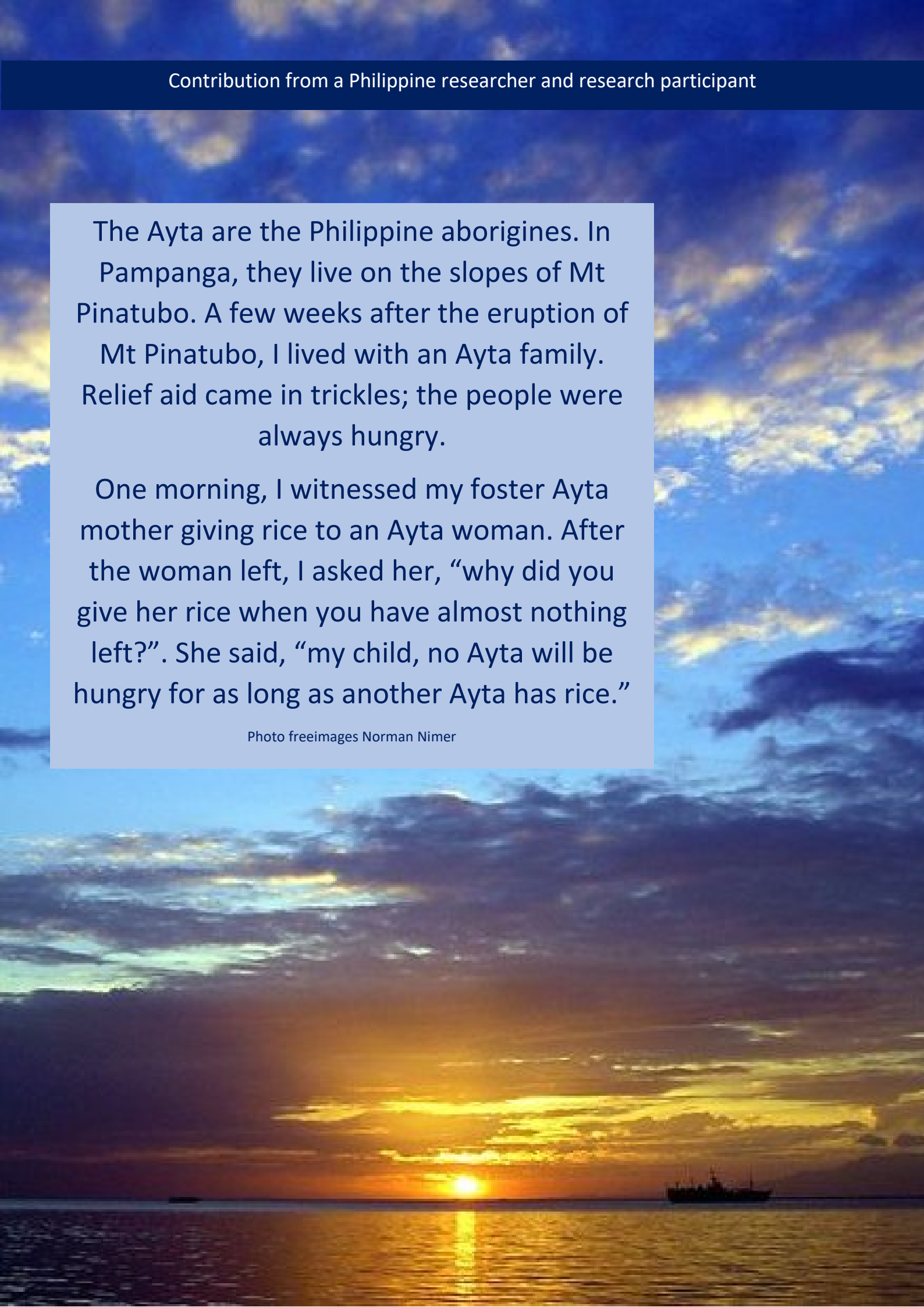
There is a growing movement called effective altruism. It's important because it combines both the heart and the head.

Peter Singer (1946)


The Ayta are the Philippine aborigines. In Pampanga, they live on the slopes of Mt Pinatubo. A few weeks after the eruption of Mt Pinatubo, I lived with an Ayta family. Relief aid came in trickles; the people were always hungry.

One morning, I witnessed my foster Ayta mother giving rice to an Ayta woman. After the woman left, I asked her, “why did you give her rice when you have almost nothing left?”. She said, “my child, no Ayta will be hungry for as long as another Ayta has rice.”

Photo freeimages Norman Nimer



Honesty



A lie has many
variations, the truth
none.

African proverb

Photo freeimages Subhadip Mukherjee

Contribution from Kenyan researcher and research participant


No legacy is so rich as
honesty.

William Shakespeare (1564-1616)



Contribution from UK researcher and research participant





Honesty saves
everyone time.

Klaus Leisinger (1947)

Ehrlichkeit spart allen Zeit.

Contribution from German researcher and research participant



Contribution from Italian researcher and research participant



In a country where everyone went around with a clean conscience, the honest were the only ones with qualms, always asking themselves what was the right thing to do.

Italo Calvino (1923-1985)

In quel paese di gente che si sentiva sempre con la coscienza a posto loro erano i soli a farsi sempre degli scrupoli, a chiedersi ogni momento cosa avrebbero dovuto fare.



The Chinese government has publicized the
“core socialist values”, including 富强
(prosperity), 民主(democracy), 文明(civility), 和
谐(harmony), 自由(freedom), 平等(equality), 公
正(justice), 法治(the rule of law), 爱国
(patriotism), 敬业(dedication), 诚信(integrity),
and 友善(friendship).

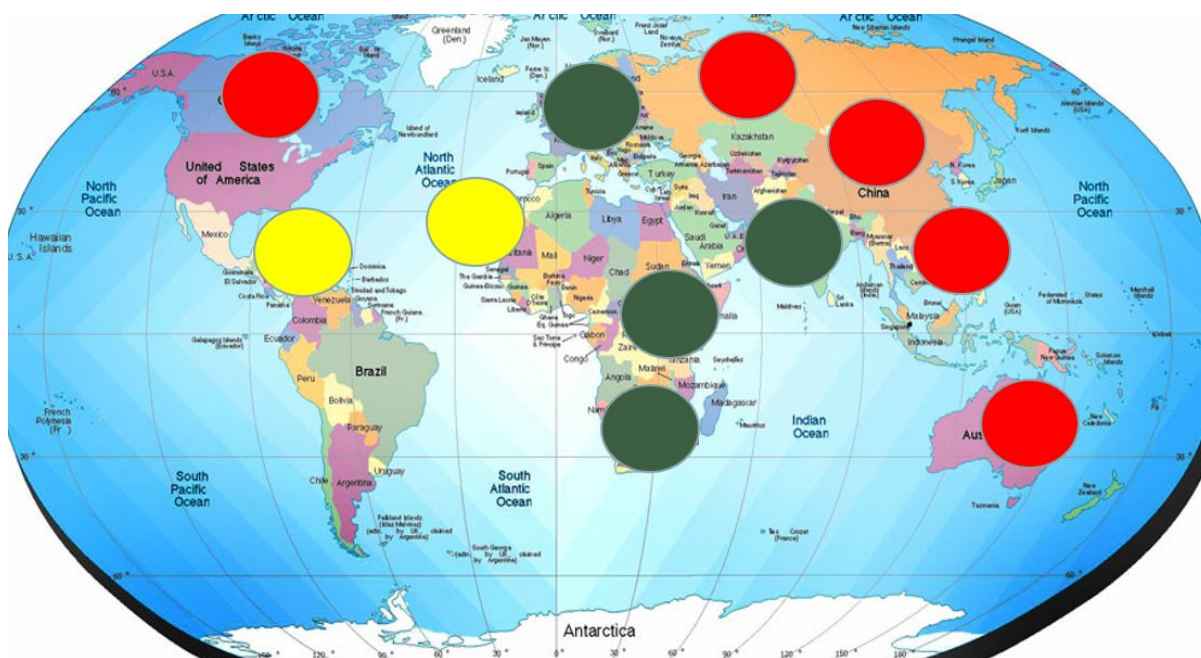
The Chinese government

Integrity goes for honesty, friendship goes
for care and respect, and justice goes for justice.

Image bought from istock

Contribution from Chinese researcher and research participant

Conclusion



TRUST has representatives from the above countries/regions, spanning five continents. All have contributed with enthusiasm to this pictorial report. The TRUST team is committed to the four TRUST values of fairness, respect, care and honesty. We hope this report provides some evidence that others are too. We would like to close with an African proverb.

If you think you are too small to make a difference, you haven't spent a night with a mosquito.
African proverb



Appendix

The following is a reproduction of the explanations for the four values from a previous deliverable.⁸

Fairness

The terms fairness, justice and equity are often used interchangeably. We have chosen the term fairness in the hope that it is / will be most widely understood globally. Philosophers commonly distinguish between four types of justice or fairness.⁹

Fairness in exchange

establishes the equity of transactions

Distributive fairness

deals with the division of existing, scarce resources amongst qualifying recipients

Corrective fairness

rights a wrong that one has brought upon another, usually through a court

Retributive fairness

establishes which punishment is appropriate for any given crime



Robert-Owen Wahl, free images

The most relevant fairness concepts in global research ethics are fairness in exchange, and corrective fairness. In North-South collaborations, as the name indicates, at least two parties are involved in a range of transactions. Typical fairness issues in global research ethics are:

- Is the research relevant to local research needs?
- Has benefit sharing taken place?
- Are LMIC authors involved in publications?

These are questions about **fairness in exchange**. For instance, LMIC research participants contribute to the progress of science, but this is only fair if the research is actually relevant to their own community.

Corrective fairness, which presupposes the availability of legal instruments and access to mechanisms to right a wrong (e.g. a complaints procedure, a court, an ethics committee) is

⁸ <http://trust-project.eu/wp-content/uploads/2016/12/TRUST-Deliverable-Generic-Risks-Final-copy.pdf>

⁹ Pogge, T. (2006). Justice. In D. M. Borchert (Ed.), Encyclopedia of philosophy 2nd ed (Vol 4) pp862–70. Detroit, MI: Macmillan Reference.

also important in North-South collaborations. For instance, if no host country research ethics structure exists, corrective fairness is limited to the research ethics structure in the Northern country, which may not have the capacity to make culturally sensitive decisions.

The broader question of what the North owes to the South falls under **distributive fairness**. One can illustrate the difference between fairness in exchange and distributive fairness using the example of post-study access to successfully tested drugs. In the first case (fairness in exchange) one could argue that research participants have contributed to the marketing of a particular drug and are therefore owed post-study access to it (should they need the drug to promote their health and well-being, and should they not have access otherwise). In the second case (distributive justice) one could provide a range of arguments, for instance the signing of the *Universal Declaration of Human Rights*, to maintain that *all* human beings who need the drug should have access to it, and not just the research participants. In this report, we focus on fairness in exchange. Likewise, **retributive fairness** is less relevant as few ethics violations fall under criminal law, where the appropriateness of punishment must be discussed.

If no host country research ethics structure exists, corrective fairness is limited to the research ethics structure in the Northern country.



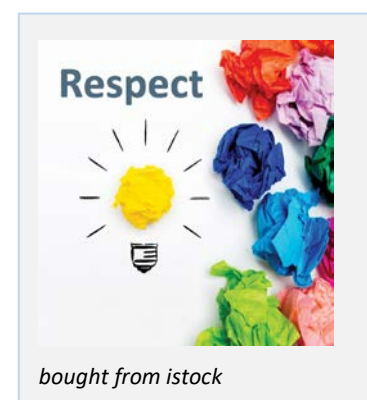
Respect

The term respect is used in many ethics frameworks. For instance, the *Declaration of Helsinki* notes in Article 7 that:

Medical research is subject to ethical standards that promote and ensure *respect* for all human subjects and protect their health and rights.¹⁰

Its ubiquitous use, however, does not mean that it is a clear term. In everyday life, it is used in the sense of deep admiration. For instance, somebody could say, “I respect the achievements of Nelson Mandela”. However, that is not what is meant by respect in research ethics. The statement from the *Declaration of Helsinki* does not mean that research participants must be admired. To be respected in research ethics is almost the opposite. It means that one must accept a decision or a way of approaching a matter, even if one disagrees strongly. A typical case in point is to respect the decision of a competent adult Jehovah’s Witness to refuse a blood transfusion, even if this means certain death.

Respect is therefore also a difficult value, as there is always the possibility that one *cannot* accept another’s decision. For instance, if a researcher learns about female genital mutilation (FGM) being used as a “cure” for diarrhoea in female babies,¹¹



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

¹¹ See case study 5 in TRUST Report on Paradigmatic Case Studies, at: <http://trust-project.eu/wp-content/uploads/2016/03/TRUST-664771-Paradigmatic-Case-Studies-WP1-Final.pdf>

respecting this approach to health care is likely to be the wrong decision - particularly as the practice is likely illegal - or at the very least a decision that would leave the researcher with a serious conflict of conscience. But being a value that may be difficult to operationalize in North-South collaborations does not mean that one can dispense with respect.

The entries in the risk table related to respect which we provide below are based on consultation with two vulnerable populations (sex workers and indigenous peoples), as well as the literature. The importance of respect in North-South collaborations cannot be ignored and there are many possible ways of showing respect that do not create conflicts of conscience. For instance, illiterate San community members should not be enrolled in research studies without contacting San leaders first, in accordance with the community norms. Or, Northern researchers should not insist that LMIC ethics committees must accept the format of their own preferred ethics approval submission, but instead submit the study for approval in the format required by the LMIC committee.

Whilst it is possibly difficult to imagine a situation where a Northern researcher is accused of being too fair, too honest or too caring, it may be possible to be accused of being 'too respectful', e.g. when faced with major violations of human rights. To find a balance between imperialist-type imposition of approaches and careless acceptance of human rights violations may sometimes be difficult, but it is what researchers should strive for.

Care

Sometimes one word describes different concepts. That is the case with "care". If somebody said, "I care for my grandmother", it could mean two diametrically opposed things. First, it could mean that the person is very attached to her grandmother but hardly ever sees her. Second, it could mean that she is the person who injects her grandmother with insulin, cooks her meals, and makes sure that her needs are taken care of on a daily basis, even if there is great dislike between them.

What we mean by the value of care in the context of global research ethics links more to the second use of the term; to look after or take care of somebody or something. As a main priority, one should take care of those enrolled in research studies to the extent that one always prioritizes their welfare 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.¹²

As a main priority, one should take care of those enrolled in research studies to the extent that one always prioritizes their welfare over any other goals.



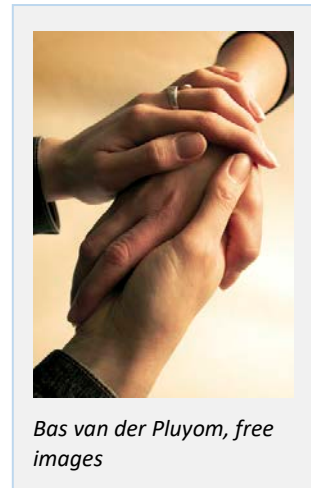
This care applies across disciplines, not just in medical research, and is also not restricted to human research participants. Article 21 of the *Declaration of Helsinki* extends the care for

¹² <http://www.wma.net/en/30publications/10policies/b3/>

welfare to research animals.¹³ Likewise, care for environmental protection is increasingly included in research ethics processes and frameworks for responsible research. For instance, the Horizon 2020 ethics review process includes establishing potentially negative impacts on the environment as part of the review process. And Richard Owen et al define responsible research and innovation as, “a collective commitment of care for the future through responsive stewardship of science and innovation in the present”,¹⁴ a statement which has clear relevance to environmental protection.

Researchers who take care to avoid negative impacts in their work will not ‘helicopter’ into a research area they are not familiar with, but will use systems of *due diligence* to ensure that risks are first assessed and taken care of. For instance, a Northern research team which strips a local area of all doctors and nurses by attracting them into their high-tech research facility does not act carefully and ethically. Acting carefully also means taking obligations in relation to research ethics seriously. For instance, an ethics review committee that exists, but is poorly staffed and trained, cannot take care effectively of the interests of research participants.

Ideally, researchers who take good care combine the two elements that were mentioned at the outset: 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).



Bas van der Pluyom, free images

Honesty

Honesty is a value that does not need complicated explanations or definitions. In all cultures and nations represented on the TRUST team, “do not lie” is a basic prerequisite for ethical human interaction. It is so basic a value that its synonyms are often broad ethics terms. For instance, according to the Google synonyms, they are:

“moral correctness, uprightness, honourableness, honour, integrity, morals, morality, ethics, principle, (high) principles, nobility, righteousness, rectitude, right-mindedness, upstandingness”.¹⁵

However, what does need explaining is the scope of the value of honesty in the context of global research 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 leave out salient features from an informed consent process. For instance, if eyes are removed and replaced with artificial ones in a research study that uses paediatric corpses, it is highly

¹³ Ibid.

¹⁴ Owen Richard, Jack Stilgoe, Phil Macnaghten, Mike Gorman, Erik Fisher, and Dave Guston. 2013. "A Framework for Responsible Innovation." In *Responsible Innovation* edited by Richard Owen, John Bessant, and Maggy Heintz, 27-50, London; John Wiley.

¹⁵ <https://www.google.de/search?q=honesty&ie=&oe=>

unethical not to inform the consenting parents or guardians of this fact.¹⁶ Whilst no lie might strictly be involved, hiding salient information also violates the value of honesty. 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.

In addition to lying and withholding information there are other ways of being dishonest, in the sense of not communicating openly and transparently. For instance, in a vulnerable population with high levels of illiteracy, it is predictable that a printed information sheet about research is not going to achieve *informed* consent. The same can be said for a refusal to overcome language barriers in a meaningful way. For instance, leaving highly technical English terms untranslated in information sheets can easily lead to misunderstandings.

Diagram 1: Honesty



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: Do not manipulate your data. Do not put your name onto publications to which you have not contributed. Do not waste research funds, to give only three examples. However, whilst the latter prescriptions for conduct with integrity in research are very important, they are not directly linked to exploitation in North-South collaborations, and are therefore not included as exploitation risks in our table. Instead, the next section summarizes the relationship between the four TRUST values and research integrity.

¹⁶ Information from case study submitted to the TRUST team, currently being verified and potentially made available on our website in 2017.