

MTb

BULLETIN of the NETHERLANDS SOCIETY for TROPICAL MEDICINE and INTERNATIONAL HEALTH

N° 03 / NOVEMBER 2022 - VOLUME 60



decolonising global health



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WALKING THE TALK

In *We Slaves of Suriname* Anton de Kom recounts the history of his homeland – from the early settlements in search of gold, through the era of slave trade and the period of Dutch colonial rule. Today, 159 years after the abolition of slavery in Suriname and 88 years after its first publication in 1934 (in Dutch), the book has lost none of its power.

The book is articulate and analytical in its examination of the mechanisms of injustice and inequality; and of the impact of slavery and the colonial system. Chilling are its descriptions of systematic exploitation, and daily life under colonial regime including the brutal punishments. Being autobiographical, it builds on personal experiences to describe how the system worked. As students, De Kom and his peers were caned when they dared to speak the Surinamese language within the school walls. Whilst searching in vain for the names of the rebels of Suriname in the textbooks, the pupils were 'expected to go into raptures about the rebelliousness of Claudius Civilis and the brave Abjuration of William the Silent'. No better way, De Kom concludes, 'to foster a sense of inferiority in a race than through this form of historical education'. It took him a long time to free himself entirely from the obsessive belief 'that a Negro is always and unreservedly inferior to any white'.^[1] The story told here – the gruesome and painful history of racism and colonialism – is told with maximum impact.

In this edition of *MTb*, and during the symposium on Decolonising Global Health, we also intend to tell a story. A story of how we can come to terms with this painful past.^[2] How we reflect on it, and how we deal with the colonial structures that – despite being formally abolished – continue to linger on in our daily lives, and in our work as professionals working in global health. In his provocative comment, Richard Horton (Editor-in-Chief, *The Lancet*) challenges us 'to undertake a more realistic and rigorous analysis of where power lies politically, economically, militarily, and culturally. Changing the names of buildings and removing statues of scientists whose pasts we now deem unacceptable, as important as these symbolic measures might seem, risk becoming illusions of action, veiling the truth concerning new regimes of authority, dominance, and privilege. Decolonisation must mean much more.'

Let's make it mean more. Enjoy the read and the symposium.

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1. Anton de Kom (1934). *We Slaves of Suriname*. English edition Polity Press 2022. Translator's note on the use of terms that express racist attitudes: instead of forcing the terms for race and skin colour into a twenty-first century mold, the translator looked for terms used by De Kom's equivalents.
2. In November 2022 the Dutch government announced how, during next year's Slavery Memorial Year (from 1 July 2023 to 1 July 2024), extra attention will be given to our historic involvement in slavery: 'a very painful, significant, and - until recently - underexposed part of our shared history'. Available at: <https://www.government.nl/ministries/ministry-of-education-culture-and-science/events/slavery-memorial-year>
3. Horton R. Offline: The myth of "decolonising global health". *Lancet*. 2021; 398:1673



Decolonising Global Health: An Introduction by Olivia Rutazibwa



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PHOTO CREDIT: FAZIL MORADI

Olivia Rutazibwa is an Assistant Professor in Human Rights and Politics at the London School of Economics and Political Science and a prominent voice in contemporary debates on decolonization. For this MTb issue, she was interviewed by Emma Pieters.

In this interview, Rutazibwa argues that in order to decolonize global health, we must acknowledge colonial histories and their continuing impact. According to Rutazibwa, decolonization efforts however should not be limited to verbal statements but must be strengthened by actions. This includes rectifying structural inequalities, created by the historical destruction and exploitation of the Global South by the Global North and by contemporary neoliberal frameworks such as Structural Adjustment Policies. Moreover, Rutazibwa suggests that we should stop thinking of emergency aid and development work as the principal solutions to global

inequities. At a more personal level, this means that people from the Global North must be willing to give up their positions of 'saviours' and 'experts'. Finally, it follows from the above that the Global North should cease to impose its own understandings of health as the only legitimate pathway on the rest of the world.

BEYOND FLAG PLANTING

Today's call for 'decolonization' implies that at present colonial structures still prevail, despite former colonies having become independent states.^[1] As Rutazibwa points out, there are various ways in which we can think about colonization. "We often assume that colonialism is just about the literal presence in another place, like 'This is my country. I plant my flag. I'm going to rule over your land and your country and your people'. But colonialism is not just that, the planting of a flag. It's also about extreme power inequalities and all the institutions that exist to keep them in place." Based on this understanding, it is evident that 'decolonization' has not

yet been fully realized. In many cases, de facto autonomy and equality have not been achieved. Despite former colonial powers having (largely) removed their flags, and former colonies having become sovereign nations on paper, the first have continued to exert control and influence over the latter. To illustrate her point, Rutazibwa takes the case of West Africa as an example. Even though countries in West Africa got their formal independence from France in the 1960s, France still dominates these countries militarily, culturally, and economically to this day.^[2] Identifying this phenomenon, Ghana's first president Kwame Nkrumah (1960-1966) coined the term 'neo-colonialism'.^[3] Rutazibwa: "Just immediately after Ghana's independence Nkrumah articulated this observation of 'I know you guys left, but somehow we're still dependent on you'. So this understanding has always been there. The call for decolonisation in that sense is not a new phenomenon, but a resurgence."

Another way to think of colonialism is in terms of destruction, extraction, and imposition.^[4,5,6] Imposition refers



to one group of people imposing their ideas and their ways of organizing the world on others. As Rutazibwa points out, imposition in this sense has marked global health systems just as much as other areas of society. *“The homogenizing imposition that is inherent to colonialism is evident in how one way of thinking about global health prevails. In most medical schools around the globe, Western medicine is being taught. In fact, it has been formalized to the extent that we don’t even have to say ‘Western’ when we refer to it – it’s just called medicine. So there’s very little variation. Even if you spent your entire life in Nigeria and you go to the University of Lagos to do medicine, the likelihood is that you will only get one particular version of medical science, which is the Western version. So that’s a form of imposition.”* Rutazibwa explains that the imposition of Western medical knowledge, and the simultaneous loss of other medical knowledges did not just happen overnight but are the consequence of historical processes. *“An important aspect of colonialism is the destruction of people, knowledge, and living environments, respectively genocide, epistemicide and ecocide. In the context of slavery and colonialism, millions of people died. Conjointly with their killing, their ways of thinking and sense-making were erased or marginalized, and their environments often destroyed or depleted through extraction. In that context, alternative forms of healing and of medicine have been discarded as not being significant or valid.”*

NOW AND THEN: INTERLINKED PROCESSES

According to Rutazibwa, the imposition of ‘Western’ knowledge and destruction of other knowledges has been accompanied by a discourse of superiority that can be traced back to the 15th century. As Columbus and his contemporaries ‘discovered’ faraway lands, a debate on the humanity of the peoples inhabiting these places unfolded. ‘Humanity’ in this context was measured by the extent to which these peoples were thought to know or to be known by the god of the Europeans that invaded their lands. An important benchmark of ‘humanity’ was therefore considered to be Christianity. Rutazibwa: *“The question that then comes up, is ‘Are they convertible?’. If the answer*

is ‘yes’, it means they are to be human, because they’re children of God. This in turn means that they have to be treated in certain ways, based on their humanity. But from this same logic it follows that if they are peoples without God, who cannot be converted, that they are not fully human. In this case they don’t have to be treated like humans. So people were dehumanized, or their humanity was made conditional. And this carried on throughout the enslavement of Africans and their kidnapping and transportation to the Americas.”

During these same times, civilization ideologies took shape. For if people were to be converted, it was the self-assigned task of the Europeans to facilitate this process – who else would be able to ‘civilize’ these people to conform to their Christian standards? Conversion and civilization efforts thus went hand in hand with notions of superiority. As Rutazibwa argues, these notions of superiority are still discernible today: *“The civilizational ideologies of that time have passed through to the present. The underlying idea is ‘We can save those souls, but our presence is needed’. So we are going to teach them how to read and write, how to do medicine and how to be converted to Christianity. In a weird way, racist ideologies have always shifted between completely denying other people’s humanity or making their humanity conditional upon us converting them to something.”* As Rutazibwa points out, these persisting notions of superiority – be it disguised as ‘expertise’ or saviourism – are completely misguided, as they fail to take into account the histories that caused today’s inequalities. Moreover, they fail to recognize the correlation between the ‘here’ and ‘there’, for many contemporary problems in the Global South can be traced back to the malpractices during imperial and colonial times perpetrated by the Global North.^[7] In her article *On Babies and Bathwater*, Rutazibwa therefore advocates for a humbler attitude of countries, organizations, and individuals from the Global North that operate within the Global South.^[8] *“We cannot detach the origin of wealth in the West from the origin of poverty in the rest of the world, which then means that you cannot just go out there with your wealth and say, ‘I’m going to help’. We’ll*

have to go out there and say, ‘How can I rectify this?’. When you acknowledge the historical context, it’s untenable to think about it in terms of ‘development’ or ‘aid’. Instead, we should think about it as justice and reparations. The invitation to take history seriously is not just about studying it and mentioning it, but it’s actually trying to think about: ‘What are the consequences of the fact that I stop pretending that this never happened?’”

BAND-AID AND STRUCTURAL SOLUTIONS

Structural change begins with acknowledging that emergency aid is not part of the solution, Rutazibwa argues. *“The problem with a lot of global health or international aid systems, is that emergency support has been confused with the real solution that brings about the correction or the justice. But it is nothing more than a band-aid.”* As Rutazibwa points out, the field of development work, including global health, has become entangled in technical discussions on the optimization of foreign aid. In focusing on the technical aspects of development and aid work, the sector greatly undermines a critical assessment of its functioning in a larger framework. *“In mainstream conversations, we hardly ever seriously ask the question of whether a Western presence is something positive or negative. It’s assumed to be positive because the Global North has more money. And if people are there with good intentions, then at least they can help. But if you take a historical approach to this, there is very little evidence that Western presence aimed at ‘development’ ever brought something positive to the Global South.”* To address issues such as access to health services, or medicine availability and affordability, Rutazibwa thinks we should start looking at the broader structures that keep global inequalities in place. *“We should start addressing the whole setup of the global pharmaceutical industry for this explains much better why people don’t have access to whatever could cure them than anything else. We have to start thinking about prices, intellectual property rights and patents, all of that.”*

Rutazibwa is however not saying that emergency aid should come to a halt. *“It’s not a zero-sum game. It’s not either this or that. But I think the invitation*



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that the call for decolonization brings, is to somehow expand our imagination of solutions and to understand that when you do fly out on an emergency mission, and you save peoples' lives, that you understand that you're not part of the full solution. But there is never a moment where you should say, let's not save lives. So that's the thing. You have to save lives. But one of the things that acknowledging the past does, is that you come up with better solutions for the present as well". ^[9,10]



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Olivia Rutazibwa biography

Dr. Olivia Rutazibwa (1979) is a Belgian/Rwandan scholar and former journalist. She holds a PhD in Political Science and International Relations from Ghent University. Before her current position at the London School of Economics (LSE) as Assistant Professor in Human Rights and Politics, Rutazibwa was Senior Lecturer in European and International Development Studies at the University of Portsmouth. Throughout her career, Rutazibwa has been advocating for the decolonisation of development work and aid. In doing so, Rutazibwa does not limit the conversation to academic spheres, but instead makes regular appearances at various media platforms, such as TedxFlanders and Zwijgen is Geen Optie. ^[1, 2]

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10. For more by Olivia Rutazibwa, see: Rutazibwa O. TedxFlanders. 2011. Available from: <https://tedxflanders.com/conferences/talks/>

"BUT COLONIALISM IS NOT JUST THAT, THE PLANTING OF A FLAG. IT'S ALSO ABOUT EXTREME POWER INEQUALITIES AND ALL THE INSTITUTIONS THAT EXIST TO KEEP THEM IN PLACE."



Is Global Medicine under threat?

Medicine often has pictured itself as a kind of pacifist, internationally orientated profession, committed to preserving life everywhere. Humanity's health in its entirety was its goal and doctors all over the world worked together to this end. But we know that the medical profession hasn't always been so innocent or committed, and this is putting it mildly. In fact, medicine can be seen to mirror the zeitgeist: in moments of international cooperation, medicine has been internationalist, in times of state conflict medicine has been nationalistic. In the age of colonialism, medicine was colonialist.

Tropical medicine and the societies for tropical medicine date from colonial times. Set up around 1900, they purported to be universalist and international, with doctors from different countries working together in the research institutes of British India or the Netherlands East Indies. However, the drive behind setting up these *national* societies was nationalistic and imperialist: 'We' have to come up with cures for 'our' illnesses and treat 'our' patients. The research programs of colonial medical institutions were fitted into the colonial plans. Illnesses endangering the white elite – and the natives working for them – had preference. Racist ideas on illness were broadly discussed, shared and accepted.

To give but two examples: around nineteen thirties two of the employees of the famous Eijkman Institute were German national socialists who later in the nineteen thirties were responsible for setting up the *Kolonial Blut Gesetz* (colonial blood law). Nobody complained. Schools for preparing doctors who wanted to work in the tropics were placed in the 'motherlands' and not in the colonies, which would have been far more logical. Although often seen as points of pride by the former colonial powers, the tropical medical institutes practiced and promoted not so much tropical as colonial medicine.

Decolonisation changed this. Doctors wanting to work in the tropics found a new milieu; their workplace became truly global. The post-colonial 'diaspora of tropical doctors' turned out to be the cornerstone of emerging international healthcare. The foundation of the Alma Ata agreements, and medical policies like Primary Health Care and Health for All weren't laid by medical-humanitarian impulses but rather by international politics. This resulted in a new kind of tropical doctor: no longer was a foreign country their home, but they went abroad for a couple of years after which they returned., but he *and she* went abroad for a couple of years after which they returned and/or sought a new location. These doctors still came largely from the former colonial powers. What these doctors did was no longer dictated by their own (largely former colonial) governments, but by the governments of the often newly independent countries in which they were working as well.

This certainly is one of the reasons that curing disease – the archetypical tropical medicine – although of major importance still, shifted to preventing disease, to attention for the socio-economic and political causes of disease. It shifted, in other words, to international healthcare, a shift politically influenced and set in stone by the Millennium Development Goals, the MDGs. This process was strengthened by the explosion of travel and communication means and by the fact that traveling the globe no longer was a Western prerogative. Doctors from the so-called 'third world' went to the former colonizing countries learning their trade (and often staying there), and, more importantly, many others went there as well (migrants, refugees, et cetera), bringing with them the formerly so-called 'tropical' medical diseases.

Globalization, aggravated by – and in part cause of – global warming, increases the risk of pandemics, making truly global medical and public health policies more important than ever. But international cooperation in healthcare continues to be constrained by national borders which, firstly, have only proliferated with decolonisation, and, secondly, are increasingly considered to be of more importance in the last few decades, especially in the Western world. Projects in low- and middle-income countries (LICs) have to be of national interest. Ministries for Development Aid vanish and Ministries of National Health and Family Values arise. Women's and other human rights are under threat, annulled or simply denied.

Although it is too early to predict what the exact consequences of these processes will be, they undoubtedly will affect international healthcare and global medicine – and not for the better. Also, there will certainly be health professionals who agree with the above nationalistic, right-wing development. Let's hope they do not succeed, and let us strive to ensure that these viewpoints do not spread and do not threaten what is the core essence of a truly *global* medicine.



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The Dutch vision and strategy on Global Health in times of multiple crises

Last month, the first-ever Dutch Global Health Strategy (DGHS) was released.^[1] Developed jointly by the Ministry of Foreign Affairs (MFA) and Ministry of Health (MoH), the strategy will be implemented by both ministries and in cooperation with others. While we welcome this collaborative integrated government approach, which we have long argued for, there are several considerations relevant to the actual implementation of the DGHS.^[2] In this article, we will begin to unpack the strategy by positioning the policy within a wider context, and looking at its role and significance for our country's foreign and domestic health policy. We will address the main topics and approaches, and focus on three elements that require greater scrutiny: (1) The support to further privatisation of health services; (2) The role of the Netherlands in ensuring policy coherence for development objectives; and (3) the focus on health security and One Health policies. In the final section, we provide recommendations on how to take this strategy forward, considering good governance and democratic legitimacy.

THE RISE AND FALL OF GLOBAL HEALTH

David Fidler wrote in 2011 that although global health had become a prominent foreign policy issue in previous decades, political attention to the subject was declining.^[3] Commitments and development funding had been made available by western governments for certain aspects of global health. HIV/AIDS prevention and treatment received a huge boost, as did other infectious diseases. Social health protection and micro-insurances schemes were in fashion in the field of health economics, and other support was devoted to strengthening health systems and human rights – with particular attention given to primary health care, access

to medicines, and sexual and reproductive health and rights (SRHR). At the same time, there was less attention given to social determinants of health (SDH) and non-communicable diseases, such as diabetes – particularly in low and-middle Income countries (LMICs).

Major challenges in the wake of the financial crisis resulting from the worldwide international financial crisis 2008-2009 required attention at national / domestic levels.^[4] Afterwards, there was more of a focus on other issues that emerged, such as refugee and migrant flows, terrorism, and international security concerns. Global Health policy became less of a priority in Europe.

During that period, up to 2015, global health strategies were developed by the UK, US, the EU and several countries in Europe, though implementation lagged behind.^[5] Multilateral funding for health stagnated and western governments opted for dealing with business actors and philanthropists. They preferred to leverage foreign financial investments via Sustainable Development Goal 17, referring to multi-stakeholder partnerships.

Interest in global health also diminished in the Netherlands: for example, funding of the interdisciplinary Global Health Policy platform was halted.^[6] Publications with a critical analysis – like the Netherlands Centre for Sustainable Development (NCDO) publication on global health needs and the role of the Netherlands – were shelved.^[7] Meanwhile, the government invested in public-private partnerships, among others in the life sciences and health domain (through 'Top Sector' subsidies).^[8] In 2011, the focus of development cooperation was narrowed down to just four spearheads, one being SRHR (besides, food, water, and security & rule of law).^[9] Other global health topics received less interest, hence less funding from the MFA and

related agencies. Simultaneously, the MoH mainly focused on one particular issue, Anti-Microbial Resistance (AMR).

THE COVID-19 PANDEMIC AND ONE HEALTH SPIRIT

The pandemic made a difference and times seem to have changed. Covid-19 had a much bigger global impact than earlier outbreaks of infectious diseases like Ebola and Zika or the (latent) crisis as a result of AMR. Politics shape health and disease, but epidemics also shape history and politics. As the pandemic hit the centres of the global financial economy (e.g. Shanghai, London, New York), swift action and massive public investments followed. After some initial hesitation, EU member states and the European Commission stepped in to prevent an economic meltdown and social disruption. It has even been argued that the European Covid-19 pandemonium, with all its ups and down, has enabled Europe to become more strategically 'autonomous'.^[10] The European political space develops through periods of political crisis. The pandemic has been such a political crisis.

The realisation that future pandemics are likely, and that these are related to economic inequities, food insecurity, and the biodiversity and climate crises compelled the government to develop a global health strategy. The strategy was developed in consultation with several actors (10), and integrates key principles from a thematically related policy report from the Dutch Advisory Council on Foreign Relations.^[11] Due to political pressure, the strategy was developed remarkably quickly (in less than 6 months) – a commendable achievement, though it is questionable to what extent it reflects the dialogue and representation of all parties engaged in the process.

The new strategy is convincingly structured on three overarching themes:



(1) Strengthening global health architecture and national health systems; (2) Improving international pandemic preparedness and minimizing cross-border health threats; (3) Addressing the impact of climate change on public health, and coordinating intersectoral policies including water management and food security. It also promotes responsibilities and commitments to multilateralism, a policy action perspective, principles for policy coherence, and contextualised approaches. The strategy is hence a strong basis for a more specific intersectoral global health action plan, including indicators, timelines and budgetary approaches. Nevertheless, some elements are downplayed or neglected in the strategy. Broadly, these are the following.

First, Wemos already pointed out that the strategy is overly positive about the role of the private health sector.^[12] Several claims are made about the contributions of Dutch commercial and philanthropic initiatives in strengthening health systems. This perspective is misleading. We see that in many LMICs progress in Universal Health Coverage (UHC) has stalled in the wake of the Covid-19 crisis.^[13] By now, there is abundant evidence that private sector involvement requires countries to develop and implement context-specific and appropriate policy and regulatory instruments and a workforce to implement them. Moreover, accountability mechanisms are needed to ensure that any public-private partnerships serve the health of the population and the goal of UHC.^[14] However, LMIC authorities are often unable or unwilling to regulate the private health sector, given the financial power of the transnational medical companies involved and the conflicts of interest involved.^[15]

Second, with regard to the Do No Harm principle, improving food security, access to medicines, and promotion of policy coherence, there is too little recognition of the structural role that the Netherlands and several Dutch non-state actors have had in actually undermining public health systems, common goods, and development processes in LMICs. For example, Dutch

transnational corporations in the food domain contribute to driving commercial determinants of health that are leading to an obesity and NCD epidemic in children and young adults in LMICs as well as in Europe itself. These determinants include the promotion of sugary drinks and ultra-processed foods.^[16] These are also promoted through EU trade agreements with countries and regions around the world.^[17]

The DGHS promotes local production of medicines and vaccines and mentions its experience with Product Development Partnerships. However, the EU, and hereby implicitly NL, has eventually abandoned the global public goods approach in ensuring access to Covid-19 vaccines globally. The EU continues to defend, via trade policies, the private monopolies and intellectual properties owned by a handful of pharmaceutical corporations, thereby undermining access to essential medical products.^[18] Indeed, there is policy coherence in the NL approach, but one could cynically argue that these actually benefit private financial interests instead of minimizing global public health risks and actually do more harm than good.

Lastly, with the One Health focus and attention on pandemic prevention, preparedness and risk, as well as anticipating the impact of climate change, there is a strong focus on health security and risk management. The question here is: health security for whom and security from what is being prioritized?^[19] The focus is on transnational health threats and enhancing the structures, means and capacity to contain these risks, mostly identified as infectious disease threats. But these risks are in general considered risks for European countries. Health risks are far from evenly distributed in our globalized societies. While there is a strong focus on the One Health approach to mitigating the zoonoses, Antimicrobial Resistance, and viral pathogens that could lead to epidemic episodes, there is relative silence about other, more structural health risks in other parts of this world.^[20] For instance, in most African countries Covid-19 was only a minor problem.^[21]

In Africa, South East Asia and the Middle-East, health issues are related above all to economic impoverishment and food insecurity. It is also difficult to organize health services for migrant and refugee populations that have increased tremendously due to conflicts and extreme weather events.^[22] The strategy does not mention the health situation in fragile contexts and states, whereas in 2022 fragile contexts involve a quarter (24%, 1.9 billion) of the world's population, most of them living in extreme poverty.^[23] On top of this, comes a shortage of health workers, and here also the West plays a role by attracting doctors and nurses.

IMPLEMENTING A GLOBAL HEALTH STRATEGY: THE DEVIL IS IN THE DETAILS

Let us consider that the glass is half full. The DGHS, original in its ambition and intersectoral scope, provides a decent basis for 'the start of a process – together with relevant partners – to arrive at an agenda based on set priorities, so that we can best contribute to a healthier future for the world and the Netherlands.'^[1] The strategy also forms a solid basis to contribute to the debate on a new EU global health strategy. There are some governance mechanisms outlined in the strategy on how to follow up with implementation. There is reference to a) an interdepartmental steering committee b) a Dutch Global Health Hub and c) the need for international coordination. These are all much needed and relevant, though the following considerations are relevant in that regard.

Most importantly, the initiation of an interdepartmental steering committee should be followed by a Terms of Reference that outlines mandate, responsibilities, leadership, governance modalities, and policy frameworks that the committee can work with. What is the timeline of action, what is the budgetary space of the committee, and how can it be kept accountable when an implementation plan is agreed upon? Although the MoH and the MFA have a shared mandate to lead the DGHS implementation, technical global health policy expertise is mainly at the MoH, while the DGHS budget is earmarked according to the budget

lines in the MFA'S Strategy for foreign trade and development cooperation. ^[24] This division requires clarification and a shared responsibility approach.

Furthermore, there are also considerations on the modalities of collaboration with non-government actors and how to prevent any conflicts of interests. How to ensure that the political 'fashion of the day' does not interfere with a longer-term agenda and its sustainability, while allowing adaptiveness in relation to upcoming crises? In most countries with global health strategies, it has proven difficult to sustain structure and such agenda implementation. ^[5]

A clear aim and budget are also relevant for the development of a global health hub. Will such a hub have a clear meaningful mandate? Will it be structurally financed and analytically supported via a secretariat, or is it merely a 'talk shop and networking place' for those who can afford time to participate? This relates to questions of democratic legitimacy: what is the input legitimacy of those involved, which constituencies do they represent, and how is policy dialogue and discussion promoted? Then there is the output legitimacy: how to keep such a hub and its programme accountable, how to guarantee transparency of the actors involved, including the interests they may bring, and lastly how to ensure that the hub is actually relevant and effective? ^[26]

Regarding international collaboration, similar questions can be asked: will commitments to multilateralism actually improve much needed collaboration on global public goods or will it actually further fragment the landscape? Will the focus be on the WHO or rather on other initiatives such as the global public private partnerships? A decent mapping and power analysis is required here. ^[27] In this respect, recent discussions during the World Health Summit in Berlin ^[28] illustrate different (critical) viewpoints on what kind of partnerships are preferable and what kind of actors are excluded. The One Health approach and upcoming global health strategy by the EU are expected to focus primarily on health security. Here also

there may be questions about whose security and interests are served and who is actually neglected. This may enhance European strategic autonomy, but is this considered legitimate by non-European countries? To what extent are matters like debt relief or debt restructuring for LMIC considered in these times of multiple crises? This necessitates open and honest policy dialogues with international partners.

In short, the next steps in the implementation of the global health strategy need to be inclusive. Consultations with relevant stakeholders and the general public may take some time since trust in government, science and politics has declined in these times of polarisation and multi-crisis. Attention to democratic processes and governance processes are hence important, as they seem to be much under pressure. ^[29] With so much attention on multi-crisis management, including in the DGHS, we emphasize that concerted action and responsibility by the richer countries is still needed to eradicate the structural conditions of poverty that cause the spread of a disease such as Covid-19 on a world scale. ^[30] Health and disease are a transnational concern, and a genuine Dutch contribution that addresses health concerns of international partners could stretch beyond narrowly defined interests and recognise that societies share a destiny for health and wellbeing on this small planet.



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Fatima Hassan on Covid-19 and Vaccine Equity



PHOTO CREDIT: BARRY CHRISTIANSON

Fatima Hassan is a South African human rights lawyer and social justice activist. She is the founder of the Health Justice Initiative. In 2022, Hassan received the Calgary Peace Prize for her commitment to global health equality and her fight against racism and legacies of colonialism. Hassan's efforts to combat injustices have been especially apparent in her work regarding HIV/AIDS and, more recently, in how she challenged global COVID-19 vaccine inequality. Fatima Hassan was interviewed by Emma Pieters.

It is March 2020, COVID-19 is now officially a 'global pandemic', and some people argue that the world as we know it has ceased to exist. Fatima Hassan is not one of them. To her, the way the world functions appears all too familiar. Initial statements and displays of solidarity are soon replaced by actions marked by selfishness, Hassan observes. Even though the situation is indeed a novel one, the way that the Global South and Global North interact much resembles pre-pandemic times. Many of the previous mechanisms of our global health systems prevail.

Despite the new circumstances urgently requiring alternative measures, the international patents regimes largely persist to constrain vaccine manufacturing, and pharmaceutical firms continue to dictate medicine production and distribution. This article retells the story of the COVID-19 pandemic through the eyes of Fatima Hassan, taking South Africa as a starting point.

SOLIDARITY QUICKLY DIES OUT

Just a few days after COVID-19 is coined a 'global pandemic' by the World Health Organization (WHO), South African President Cyril Ramaphose declares a 'national state of disaster'.^[1,2] It is during these early days of the pandemic that sentiments of solidarity dominate. In a debriefing on the pandemic, WHO Director-General Tedros Adhanom Ghebreyesus states: "Solidarity must be at the centre of our efforts to defeat COVID-19".^[2] Initially, this principle seems to translate into actions. South Africa, for example, receives medical tools from China in April 2020, including 61,000 masks, 3,000 protective suits and 11,000 pairs of surgical gloves.^[3] Moreover, it is around this time that the Solidarity Response Fund is created to raise money to help countries respond to the pandemic, and that COVID-19 Vaccines Global Access (COVAX) is established "to accelerate the development and manufacture of COVID-19 vaccines and to guarantee fair and equitable access for every country in the world".^[4,5] But as Hassan explains, these efforts soon reach their limits: "So the initial idea was that there would be solidarity; there was a lot of public funding and investment in accelerating vaccine research, and people were encouraged to participate in clinical trials. But what you then saw was a total refusal to share either supplies or knowledge – even with people on the frontline, or with people with limited mobility or older than 70 years."

As the pandemic progresses, pharmaceutical firms and governments from the Global North prove unwilling to

cooperate with initiatives aimed at equal access to medical resources. The reluctance to exchange knowledge and supplies makes it hard, if not impossible for COVAX – targeted at vaccine equity – to realize its goals. Moreover, as Hassan points out, countries from the Global North circumvent COVAX in their pursuit of vaccines: "The Global North entered into its own bilateral agreements with the pharmaceutical companies – some of them bypassing COVAX, some of them drawing on COVAX supplies. So the mechanisms meant to address equitable allocation, and voluntary cooperation of the industry did not materialize for a long time. It was tied into a system where the big pharmaceutical companies were calling all the shots."

The WHO COVID-19 Technology Access Pool (C-TAP) made another effort to facilitate vaccine technology exchanges, but the pharmaceutical firms that were among the first to develop a vaccine, such as Pfizer and Moderna, shared their knowledge only sparsely. Hassan: "The Global South said, 'Look there is existing manufacturing capacity in many parts of the world, we can help you scale up'. But the companies refused. The WHO created C-Tap, where the exchanges would be on the pharma companies' terms and voluntary. There would be a lot of controls or sitting down with the companies, and they were to get royalties." But, as Hassan points out, every single manufacturer has refused to even enter C-Tap.

As countries from the Global North were making sure to secure their own supplies, South Africa found itself in a disadvantaged situation – 'trying to play catch-up to the rest of the world', as Hassan puts it. In March 2021, it is reported that political entities 'representing only 16% of the global population have secured 70% of the available doses for the five leading vaccines in 2021'.^[6] Consequently, only a few countries had vaccinated significant parts of their population, while other countries were still unable to administer their



first shot. For example: by 24 May 2021, South Africa had vaccinated 642,382 (1.1%) of its population in contrast to 5.67 million (32.3%) in the Netherlands.

TOO LITTLE TOO LATE

According to Hassan, both the access to resources and the timing of when resources were made available have been essential in dealing with COVID-19. “The timing of how fast or quickly you could vaccinate large numbers of people determined whether your borders could remain open, whether your economy could carry on, if you could flatten the curve, and if you could manage lockdowns. So the timing in this pandemic of access to resources such as vaccines obviously has been critical and important.” Hassan elaborates: “In the last part of 2021, you saw a lot of donations of supplies coming in with very short expiry dates, and of vaccines that were no longer being used in the Global North. It is not helpful if you’re going to give us Johnson & Johnson vaccines now – even if it would have been before. What we need right now is an Omicron-class vaccine.”

South Africa was caught up in a situation in which it was responding to the pandemic without all the available tools that European countries or the US for example had. Hassan: “This meant that there was a drip-feed of supplies, not just of vaccines, but also of other elements that you needed to contain the menace of the pandemic, including diagnostic and testing kits as well as treatment options”. Even in the case of vaccines manufactured in South Africa, Europeans were prioritized over South Africans. In August 2021, it was exposed by the New York Times that while South Africa (with then only 7% of its population vaccinated) had still not received a major part of the 31 million doses it ordered from Johnson & Johnson, the pharmaceutical firm was exporting millions of doses from its South African plant to Europe.^[7]

An important part of the problem has been the global dependency on just a few vaccine manufacturers, explains Hassan. “If you don’t have enough manufacturers in the system in the middle

of a global pandemic, and you need to vaccinate not a few million people but a few billion people at the same time, then you maybe need more manufacturers in the system to help you scale up. Because if your plant goes down, or if there is an interruption in the supply chain, you’ve basically put all your eggs into one basket.” To illustrate her point, Hassan refers to production deficiencies with the Johnson & Johnson plant in Baltimore in 2021, and with the Covaxin plant in Hyderabad more recently.^[8,9]

SILVER LININGS: THE MRNA-HUB AND THE TRIPS WAIVER

More than a year into the pandemic, as initiatives such as C-TAP and COVAX are still failing to deliver, and many countries in the Global South are still struggling with access to medicine supplies and vaccines, the mRNA hub is established. The hub, which is located at Afrigen, Cape Town, is aimed at technology transfer and ‘build[ing] capacity in low- and middle-income countries to produce mRNA vaccines’.^[10] The creation of this mRNA hub forms a concrete attempt for the Global South to gain control over the vaccine production and distribution. Especially with the temporary loosening of intellectual property in June this year – almost two years after it was first proposed by South Africa and India – the functioning of the mRNA hub has been further enabled (although the TRIPS waiver has been criticized for being very limited).^[11] Hassan: “Both Pfizer-BioNTech and Moderna have refused to cooperate with the mRNA Hub. And the hub I think is a combination of everything that went wrong in this global pandemic, with the Global South saying, ‘Right, enough, we’re going to try a totally different model of generating knowledge, of product development, and of putting potential vaccines – not just for COVID but maybe even HIV – onto the market.’ Equity is only possible if the Global South is no longer dependent on the ‘goodwill’ of the Global North. Hassan: “If you’re relying on the existing model, which is really heavily influenced by Global North countries and the pharmaceutical industry, then you’re not going to ensure equity”. As the case of South Africa during the

COVID-19 pandemic has shown – and is still showing – the way that vaccines are commonly produced and distributed frustrates vaccine equity. But according to Hassan, the establishment of the mRNA hub and the TRIPS waiver are silver linings. “So the bottom line is that there is now this amazing effort called the mRNA hub. And if it can replicate the mRNA vaccine, without the supporting cooperation of Moderna and Pfizer, then I think that would be one of the more heartening and more positive aspects of this pandemic, with which we can show that the Global South can basically do this without these big pharmaceutical companies and without the vested interests trying to prevent it.”



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Bats, parachutes and bridges



How can epidemiologists improve global health research practice?

Imagine the scenario. A group of epidemiologists is investigating the origins of a new infectious disease in and around the area where “patient zero” is thought to have lived. The epidemiologists hypothesise that a certain type of bat may be responsible for spreading the disease. They plan a household survey, hoping to link the occurrence of disease with people’s contact with these animals. They carry with them pictures of the bats to show, but disappointingly, in interview after interview, people report having never seen the creatures.

That is until during one interview, when a perplexed researcher notices one of the bats flying overhead. Now it is the respondent’s turn to be confused. “What, that one?” they ask. “But it’s so big! The bat in the picture is tiny compared to this one. We don’t have tiny bats here, only big ones. You should have said it was big!”

This is a textbook example of what can go wrong with “parachute studies” – a term used to describe research projects conducted by researchers who are “parachuted in”, lack familiarity with a local situation, and disregard local knowledge systems and expertise. This “tiny bat” story – brief as it is – is emblematic of a much wider set of problems in global health, concerning research integrity and research fairness.

TINY BAT, BIGGER PROBLEMS

Integrity and fairness, and the lack thereof, feature prominently in our “tiny bat” story. On the issue of research integrity, we have a photo which poorly represents the bat in question. It is an ill-designed survey tool, probably developed in a hurry and not

adequately pre-tested, which will lead to information bias. If a respondent had not pointed out the researchers’ error, the epidemiologists might have unwittingly drawn the wrong conclusions from their investigations but still published their findings anyway, meaning that those study findings are unlikely to be reproducible (unless other studies use a similarly flawed survey tool!).

Irreproducibility of findings is a concern as it can fuel mistrust of science. It is also a research integrity issue: irreproducibility may arise from innocent mistakes or poor research methods (as in the “tiny bat” story). At worst, it can be the result of deliberate misconduct and fraud.

As for research fairness, imagine that our epidemiologists are from a European university, travelling to sub-Saharan Africa to conduct their research. This recasts the story as one about a global health study involving researchers from high-income countries working in a low-income setting, which therefore prompts a number of critical questions about study conduct. Was the study conducted in close collaboration with local researchers? Were local communities and local decision makers consulted to develop useful and relevant research questions? If the poor choice of bat photo is anything to go by, the answer is, probably not.

This makes it a typical example of an unfair study, which will ultimately have limited impact at the local level, where the research is conducted. Involving local researchers, communities and decision makers not only helps to ensure better quality research, but also better and more effective communication of research findings to those who need to act on the results. And, in the long term, the involvement of local researchers

ensures the development of strong local research capacity to tackle other (perhaps even more) relevant issues.

When we talk about “fairness” and “unfairness” in this context, we refer specifically to power imbalances in global health, resulting from researchers in high-income countries being funded by organisations in high-income countries to conduct research in low- and middle-income countries. Such power imbalances can prevent local stakeholders from shaping the research agenda and competing on a level playing field in international scientific arenas.

BRIDGING THE ISSUES

In order to jointly address the issues of research integrity and research fairness in global health, epidemiologists at KIT Royal Tropical Institute developed a set of good epidemiological practice guidelines in consultation with researchers from Asia, Africa and Latin America.^[1] These BRIDGE guidelines draw from existing guidelines focused on research integrity and initiatives to increase research fairness with the aim of helping researchers in international research collaborations to produce technically sound, impactful results. The result is a set of practical tips for funders and researchers at each stage of a study, from conception and planning to the writing up of results.

A number of items from the guideline’s “study preparation” and “data collection” checklists could have helped with the “tiny bat” study. During study preparation, for instance, BRIDGE advocates for the need to “plan and execute research in partnership with local researchers” and to “establish the knowledge gap by searching the literature (peer-reviewed publications and grey literature) as well as by consulting (local) experts, representatives of affected populations and end-users”. So, early on in the study, the





BRIDGE guidelines would have helped ensure that the researchers had a reasonably good understanding of the study population's concerns and viewpoints.

Meanwhile, during data collection, the guidelines emphasise the importance of “using valid and reliable research instruments” and to “pilot test, and if possible, field test all research instruments prior to the start of effective data collection”. It is possible that pre-testing the photograph-based tool to measure the frequency of bat sightings would have revealed its flaws. Elsewhere, the guidelines remind researchers to “ensure that research instruments are locally adapted and culturally appropriate” and to “select data collection staff according to technical as well as cultural criteria”. A reflection on this criterion might have helped the researchers realise that relying on a photo in the context of the “tiny bat” study was culturally inappropriate.

The criteria for study preparation and dissemination/communication have a strong emphasis on redressing existing power imbalances in global health research, by putting local stakeholders and local researchers at the centre of the research endeavour. Indeed, the guidelines aim to ensure that local stakeholders (e.g. national and local representatives of the ministry of health, health facility workers and community members) are engaged early on in the study to ensure that the research deals with their priority problems - not the researchers'. For example, it is realistic to think that local stakeholders might have preferred that the European researchers work on strengthening the disease's routine surveillance system rather than studying its origin, as this is likely to have more tangible benefits for the local population's health. The guidelines also offer a blueprint to go beyond tokenistic involvement of local



researchers, by ensuring that they are in a position to lead analysis and dissemination efforts. For instance, the guidelines prompt researchers to agree on publication plans, data sharing agreements, and professional development (e.g. training, coaching) early on in the study. These criteria aim to strengthen local research systems, which is paramount in order to enable a comprehensive response to all diseases which affect the local population - not just the one of interest to a particular group of foreign researchers who happen to have a specific interest in bat-spread diseases at this one point in time.

Tiny bats or big bats – making mistakes and learning from them is an integral part of any scientific endeavour. Mishaps along the way can be expected and no set of guidelines will ever be enough to safeguard research from all possible blunders. But the BRIDGE guidelines hopefully can help researchers steer clear of questionable and unfair research practices that may arise, and work towards a long-term positive impact on local research systems and local communities.



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THE INVOLVEMENT OF LOCAL RESEARCHERS ENSURES THE DEVELOPMENT OF STRONG LOCAL RESEARCH CAPACITY TO TACKLE OTHER (PERHAPS EVEN MORE) RELEVANT ISSUES

Acknowledgement

Many thanks to my colleague Ente Rood for the “tiny bat” story, which originally featured neither a bat nor an epidemiological study.

* This article is a reproduction of the article “Bats, parachutes and bridges: How can epidemiologists improve global health research practice?” by Sandra Alba published in *Significance* Volume 18, Issue 4 August 2021. Link to the original article <https://rss.onlinelibrary.wiley.com/doi/full/10.1111/1740-9713.01542>

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Good for research and research for good

Using the BRIDGE guidelines to assess research integrity and research fairness in global health among Netherlands' alumni

WHAT IS THE PROBLEM?

Research integrity aims to increase the reliability and trustworthiness of research.^[1] It has gained momentum over the last decades, as witnessed by the number and wide reach of efforts to promote it. In the Netherlands, as in many other European countries, research integrity has become a cornerstone of higher education. This is witnessed by the publication of the Netherlands Code of Conduct for Research Integrity in 2018 which identifies researchers and institutions and those primarily responsible for good research and which has been adopted by all universities in the Netherlands.* Nevertheless, recent studies in the Netherlands show that over half of researchers from Dutch universities self-report to have engaged in questionable research practices in the past three years.^[2]

Applying these principles in practice in global health research can be challenging due to the multidisciplinary and transnational nature of this discipline.^[3] Equity concerns in particular should be considered, as global health research often requires collaborations involving both low- and middle-income countries (LMICs) and high-income countries (HICs).^[4]

Research fairness is a movement that explicitly addresses equity in research partnerships as a response to the fact that longstanding efforts to improve global health through research partnerships with LMICs have insufficiently translated to improved health systems in these countries.^[5,6] Part of the reason is that collaborations between LMICs and HICs have traditionally disproportionately benefitted HIC researchers.^[7] Local researchers have not been able to shape research agendas in their countries and have been bypassed in scientific publications.^[8,9] This has resulted in skewed

opportunities for professional advancement, with consequences for future funding opportunities for research.^[10,11] This, in turn, is likely to have hindered the impact of global health research on the main beneficiaries, the local communities, as their interests may not be represented properly in research objectives and the studies performed.

Conducting global health research with a dual focus on integrity and fairness is key as part of a growing awareness for the need to decolonise global health and in order to reach the Sustainable Development Goals (SDG), as emphasised by SDG17.^[12,13,14] However, little is known in terms of current practices of global health researchers: to what extent is current research conducted in line with research integrity and research fairness principles? What are the challenges? Here we report on a first pilot study to jointly appraise research integrity and fairness in a sample of Masters in Public and International Health alumni of the KIT Royal Tropical Institute in Amsterdam. The article summarises the study's approach and main results and implications while the full study report can be found online. (www.bridge-statement.org).

HOW WE INVESTIGATED IT

Recently, the BRIDGE guidelines (Bridging research integrity and

global health epidemiology) were published for good epidemiological practice with the aspiration to bridge the gap between research integrity and research fairness in global health research.^[15] These guidelines consist of 6 standards and 42 accompanying criteria, and as such, offer a useful tool to assess research practices.

We followed a mixed methods approach combining quantitative and qualitative research components. The quantitative component assessed current practices in global health research as experienced by a sample of KIT alumni who graduated from 2016 to 2020 and who had gained experience in global health research since graduating.

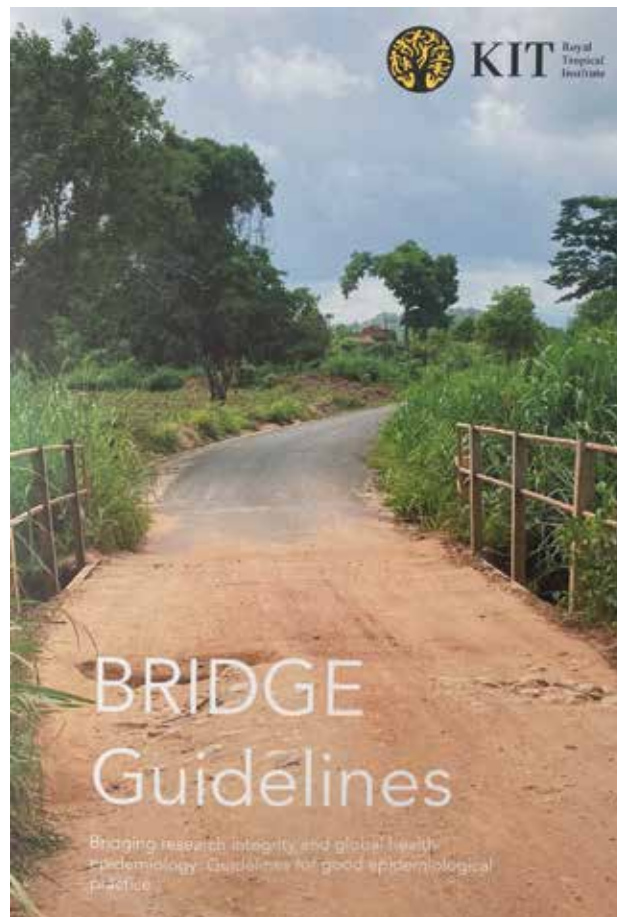


TABLE 1. Mean level of achievement per statement

Statements per standard	Mean	SD	n
STUDY PREPARATION PHASE (MEAN 3.8; SD 1.1)			
Research was planned and executed in partnership with local researchers, whilst considering current professional needs and ambitions of those involved locally.	3.90	1.04	36
Key stakeholders, including representatives of affected populations and end-users of research, were identified and engaged with consideration of their needs, competences and expectations.	3.48	1.23	36
Knowledge gaps were established by searching the literature (peer-reviewed publications and grey literature).*	3.79	1.02	36
Knowledge gaps were also established by consulting (local) experts, representatives of affected populations and end-users.*	3.51	1.20	36
Research questions and objectives were developed in consultation with research partners and expected end-users.	3.55	1.15	36
Study design and research methods were selected to best fulfil the study objectives and give due consideration to multidisciplinary approaches.	3.91	0.98	36
Before embarking on primary data collection, it was assessed whether existing data could be used, fully or partly, to fulfil the research objectives.	3.97	1.17	36
It was ensured that all research partners had agreed on data ownership and publication agreements.	3.87	1.18	36
Work plans and decision-making processes were clarified and agreed on with all study partners.	3.91	1.04	36
PROTOCOL DEVELOPMENT PHASE (MEAN 3.5; SD 1.2)			
A detailed research protocol was prepared in consultation with all research partners.	3.81	1.19	33
A clear and comprehensive analysis section was written.	3.74	1.06	33
Studying the effect of locally relevant equity dimensions was considered.	3.29	1.04	33
When conducting multidisciplinary research, the purpose and strategies to integrate different analytical methods was described in the protocol.	3.45	1.18	33
It was strived for to make study protocols publicly available, either on a publicly accessible website or in appropriate study registers.	2.93	1.41	33
For all data collection and data use concerning human subjects, ethical approval (or a waiver) was obtained from all institutions and countries involved in the protocol.	3.86	1.22	33
When working in a setting without ethical review boards or review boards with limited epidemiological capacity, endeavours were made to strengthen local research capacity.	3.33	1.40	33
Any data sharing with third parties was explicitly stated in the protocol submitted for ethical review and in the informed consent documents.	3.83	1.28	33
DATA COLLECTION PHASE (MEAN 4; SD 1.2)			
Valid and reliable research instruments were chosen, after performing a review of existing instruments and their properties.	4.11	1.13	32
It was ensured that research instruments are locally adapted and culturally appropriate.	4.10	1.14	32
Concrete guidance for data collection was provided in a document that was available to all data collection staff.	4.00	1.15	32
Data collection staff was selected according to technical as well as cultural criteria.*	3.93	1.20	32
The roles and responsibilities for each person involved were clarified for which adequate training and support was provided.*	3.93	1.26	32
All research instruments were pilot-tested and, if possible, field-tested prior to the start of effective data collection.	3.81	1.27	32
Data was collected in a respectful and safe manner and in an environment which safeguards the confidentiality of respondents.	4.29	1.21	32
Quality assurance and control mechanisms were put in place to ensure data accuracy, completeness and coherence.	3.84	1.186	32

Table continues on next page



Statements per standard	MEAN	SD	N
DATA MANAGEMENT PHASE (MEAN 3.7; SD 1.3)			
Data management procedures were put in place before effective start of data collection and concrete guidance was provided in a document available to all data management staff.	3.76	1.21	31
A data entry application was created and pre-tested prior to effective start of data collection.	3.67	1.44	31
All variables were described in a codebook.	3.41	1.27	31
Quality assurance and control mechanisms were put in place to ensure data accuracy, completeness and coherence.	3.62	1.24	31
All data cleaning and processing steps were annotated and reproducibility was strived for by means of stored programming code.	3.41	1.39	31
For each data file, levels of anonymisation and privacy protection were defined as well as corresponding access rights in line with national and international frameworks.	3.89	1.25	31
At the beginning of the study, an electronic secured study file was prepared to store all study documentation and outputs.*	3.67	1.27	31
The electronic secured study file was (or is planned to be) archived at the end of the study.*	3.86	1.21	31
Source data was retained safely, in their original form, preserving data confidentiality for as long as has been described in the protocol.	3.93	1.33	31
DATA ANALYSES PHASE (MEAN 3.6; SD 1.2)			
Only personal identifiers that are necessary to answer the research questions were worked with.	3.88	1.30	30
Statistical analyses were conducted in accordance with the protocol.*	3.88	1.30	30
When statistical analyses did deviate from the protocol, this was annotated and a distinction was made between pre-planned and exploratory analyses.*	3.45	1.18	30
All analysis steps were fully annotated and reproducibility was strived for by means of programming code.	3.24	1.14	30
In multidisciplinary studies, statistical analyses with analyses from other study disciplines were integrated in an iterative process to coherently address the research objectives.	3.36	1.26	30
Quality assurance and quality control mechanisms were put in place to ensure that data has been correctly analysed.	3.71	1.20	30
DISSEMINATION AND COMMUNICATION PHASE (MEAN 3.2; SD 1.5)			
User-specific dissemination and communication plans were developed in consultation with key stakeholders, which included (amongst others) representatives of the affected populations and end-users.	3.44	1.36	30
Data was reported in a non-stigmatising, non-discriminatory, culturally sensitive and non-identifying manner.	3.64	1.60	30
Reporting guidelines were conformed to, for the given study design and methods in academic publications.	3.50	1.50	30
Quality assurance and quality control mechanisms were put in place to ensure complete, accurate, accessible and interpretable data reporting.	3.36	1.41	30
Indexed open access journals were considered for scientific publications.	3.17	1.44	30
On study completion, reanalyses of the data by local researchers was encouraged as much as possible.*	2.48	1.59	30
On study completion, key stakeholders and research partners were consulted to identify strategies to encourage reanalyses of the data by local researchers.*	2.39	1.53	30

Table 1. Questionnaire with mean level of achievement reported on a 5-item Likert scale (1 = not achieved, 2 = slightly achieved, 3 = partially achieved, 4 = mostly achieved, 5 = completely achieved) and standard deviation (SD) per statement. N = The number of participants who answered the questions.

** Statements that were originally part of one criterion within the standard in question from the BRDIGE checklist, but split up into 2 statements.*

The BRIDGE guidelines were used to develop an online survey to rate the level of achievement of each criterion (rephrased as statement) on a 5-item Likert scale ranging from 1 for “not achieved” to 5 for “completely achieved”. The qualitative component was used to further examine and explain study participants’ views and to identify facilitators and barriers in fulfilling the BRIDGE criteria. This was done by conducting in-depth interviews in a sub-sample of the survey respondents.

WHAT WE FOUND

A total of 36 KIT alumni who were eligible responded to the online survey, of which 18 (50%) were men and 17 (47%) women. Twenty-five (69%) were from LMICs (Ghana, India, Nigeria, Mozambique, Indonesia, Myanmar, Gambia, Uganda, Kenya, Yemen, Angola and Bangladesh) and 10 (28%) were from HICs (The Netherlands, Singapore/Australia, The United Kingdom, The United States and Norway), of which Ghana and the Netherlands were the most represented (n= 6), followed by Uganda (n= 4), Nigeria (n= 3), Bangladesh and Indonesia (n= 2). One survey participant gave no home institution information. Of these 36, four alumni participated in a follow-up interview and all four alumni were from Asian or African countries.

Summary survey results can be found in Table 1, where the mean achievement scores (and standard deviations) are presented for each BRIDGE criterion and each standard. On average, respondents reported “mostly achieved” (mean = 4) for the criteria related to data collection, and in particular those related to using valid and reliable instruments, as well as local adaptation and cultural appropriateness of instruments and respectful and confidential data collection procedures. The lowest scores were reported for items related to open science practices: making study protocols available in publicly accessible websites or in appropriate study registers, publishing in open access journals, and encouragement of re-analyses of data by local researchers (around or below a mean score of 3, denoting “partially achieved”).

Communication, resources, local context, incentives and ownership were all mentioned during the interviews as main facilitators and barriers to the achievement of BRIDGE criteria. A lack of resources was often described as a main issue. Whether it concerned time, money or staff, all interviewees felt that if they had unlimited resources, they would have been better able to fulfil criteria. Many other themes mentioned in the interviews can be linked to this central one.

However, interviewees also thought that open communication and familiarity with local context were important success factors in global health research – and lack thereof an important barrier:

“When I went to the village office, to the leader, there were a lot of arguments to discuss, because I didn’t receive the first briefing, of course. It’s not equal because the village leader, he doesn’t have health education; I’m not sure. Also in the field, when I met the village midwife—there’s a village midwife—she didn’t know about the research for example. We have to make sure that the communication between all the stakeholders involved should be provided.” (Female global health researcher from LMIC in collaboration with researchers from the Global South reporting lower levels of achievement of the BRIDGE guidelines)

Data ownership and preferences for alternative formats for publication (not peer-reviewed publications) were mentioned as the most important barriers for open science practices. On the other hand, public availability of data and the encouragement of reanalyses by local researchers were directly linked with the willingness of the stakeholders involved. More specifically, the willingness of stakeholders to provide data was often linked to monetary resources and the urge to protect own interests.

However, the fear of not receiving the proper credit for one’s work seems to also be of influence with regard to the public availability of data for reanalyses.

“The people who reanalyse, maybe he do not give enough acknowledgement who actually collect the data, who are the main principal investigators. When you publish papers, or when you write an article in newspapers or for a conference [...] then everybody will give credits to you that you have done very good job. But it is actually data from another person. Actually, the audience will not know, [...]. Who present, he is the actual owner.” (Male global health researcher from LMIC in collaboration with researchers from the Global North reporting intermediate levels of achievement of the BRIDGE guidelines)

WHAT ARE THE IMPLICATIONS?

Overall this pilot study shows good self-reported achievement of the research integrity and research fairness principles in a sample of KIT alumni who are currently engaged in global health research. In particular, respectful and culturally appropriate data collection are reported as common practice which is very encouraging, though it may also be the result of a positive reporting bias. In general, findings underlined the importance of proper communication and knowledge of the local context as a pre-condition to foster both research integrity and research fairness in global health research.

However, this study does highlight some of the known tensions between research integrity and research fairness in global health, in particular with open science. Making study protocols publicly available ahead of the research study, reproducibility of analyses with stored data management and data analyses programs, and open access publishing are all hallmarks of



open science and associated attempts to ensure the reproducibility of science. These were all comparatively less frequently practiced. Furthermore, practices related to data sharing – the cornerstone of open science – were also experienced rather unfairly: efforts to promote re-analyses of data by local researchers were rather uncommon and data sharing was associated with feelings of insufficient acknowledgment and involvement of those who actually collected the data. This raises the question on how promoting open science practices may influence equity dimensions between local researchers and those who re-use their data.

HOW TO MOVE ON?

This pilot study was followed by a broader Research Integrity and Research Fairness Survey (<https://zenodo.org/record/6632009#.Y2Uu9XbMI2x>). Results from both surveys will serve as information to design a BRIDGE coaching program for global health researchers.



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Overcoming challenges to build more equitable partnerships for international medical electives

This article is based on a transdisciplinary research project initiated in February 2022. This project was designed, executed, analysed and written in collaboration with representatives from two LMICs (Malawi and Suriname) and one HIC (UMCU) medical institute (to be submitted for publication). Access to the (currently) unpublished manuscript can be granted upon request.

INTERNATIONAL MEDICAL ELECTIVES AND INEQUITY

Global health and medical education are increasingly occurring at international

and global levels, including medical students from High-Income Countries (HICs) taking international medical electives (IMEs) in Low-and Middle-Income Countries (LMICs).^[1,2] IMEs enable students to improve their clinical training, gain experience working in low-resource settings and on various diseases, and expand their worldview and cultural sensitivity.^[3–5] Host institutes can also benefit through mutual learning opportunities for the staff and students and improved institutional reputations.^[4,6,7] However, as the essential movement to decolonise global health continues, these electives have become recognised as a practice that can

perpetuate the very inequalities Global Health and Medical practitioners aim to tackle^[8]. Problems have been found when visiting students are unaware of local cultural norms and inappropriately impose 'western ideals' of health and medicine.^[4] These electives can also adversely affect local health systems through overuse of host institute time, staff and resources and the exclusion of local health workers and students from beneficial opportunities.^[1,5]

EQUITABLE PARTNERSHIPS: WHY AND HOW?

Increased awareness of such issues underlines the importance of equitable

partnerships. Equitable partnerships consider the process of individual IMEs and the wider institutional context that these electives embed themselves within. Our recent trans-disciplinary research project showed that equitable partnerships can and should be fostered through reciprocity, respectful and open communication, institutionalisation and the equitable conduct of individual IMEs.

RECIPROCITY: BALANCING BURDENS AND BENEFITS

Equitable partnerships are facilitated through reciprocity. A reciprocal partnership balances the distribution of burden with tangible and visible mutual benefits tailored to each institute's specific needs. For example, our research project showed that medical institutes with an attached academic institution can benefit from building and/or offering courses together, whereas smaller medical institutes would have little need for this kind of collaboration. Of course, some benefits are more common across contexts, such as the opportunity for student and staff bi-directional exchange. As is the case in many global health issues, challenges lie in limited funding for and low institutional prioritization of these activities. However, several non-financial benefits can be organised for the LMIC partners so this partnership still is reciprocal. Collaboration on research and educational projects, access to online university libraries, and mentorship programs are a few examples of non-financial forms of compensation. In working towards a reciprocal partnership, it is crucial to consider for whom different kinds of benefits will be tangible and who is a part of the decision-making process. For example, financial contributions to the hospital are neither visible nor tangible for many health workers involved in supervising and helping students during their IMEs. The voice and perspectives of these staff can also be missed in communications within partnerships.

TRANSPARENCY, RESPECT AND COMMUNICATION

It can be difficult to achieve an equitable partnership without partners honestly and respectfully communicating

with each other. While institutes may be open to receiving feedback, this is not enough. Participants from out LMIC partner institutes expressed the importance of them having the power and autonomy to shape the partnership. Actors from the LMIC institute must be certain their voices and expertise are respected. To avoid potential conflict or confusion, it is also important for actors to be transparent about each other's expectations, roles and responsibilities. Building equitable partnerships can become difficult when staff members from the HIC partner have mindsets that spread romanticised 'helper mindset' or 'white-saviour' ideas around these kinds of activities. It can be harmful when these mindsets are portrayed within potential communication or collaboration with the host partner, as well as when these mindsets are picked up by students during their education. Training both students and staff alike is an important part of overcoming this challenge.

INSTITUTIONALISATION AND SUSTAINABILITY

Ensuring relationships are built to last is a fundamental part of an equitable partnership. Efforts towards institutionalisation are essential in supporting a partnership's sustainability. An important step in institutionalisation is setting a clear contract between the host and visiting partner, which can also stipulate decisions made regarding mutual benefits and with whom the responsibility lies for different steps within the IME process. Sharing information and opening lines of communication on building more equitable partnerships help in both institutionalising the relationship further as well as facilitating collaboration and mutual learning. Medical institutes that have experienced failures or successes need to share these examples for others to learn from. One unforeseen positive outcome of our project was that it allowed the included LMIC partners to learn that many of the struggles they face are shared. Our focus group discussions also provided all of the included partners with an opportunity to work from both ends of the partnership to brainstorm solutions. Institutions should

avoid relying on one person to sustain the collaboration, as partnerships can fall apart if these critical individuals shift to different roles or institutions. While personal ties can help establish trusting relationships, investing in further institutionalisation will help to strengthen the partnership to withstand changing priorities and personnel.

EQUITY IN THE PROCESS OF INTERNATIONAL MEDICAL ELECTIVES

Medical electives themselves must also be conducted in a way that limits potential negative experiences and promotes positive experiences for those involved. Here, more collaboration and communication throughout all stages of IMEs, including pre-departure, during the elective, and post-departure, are essential. Some important steps that help to promote equity are:

- 1 Collaborating in setting a clear code of conduct for visiting students to cover important points such as acceptable behaviour and professional attire linked to the context.
- 2 Involving both visiting and host institutes in pre-departure preparation sessions to better coordinate information and ensure students have accurate context-specific knowledge.
- 3 Ensuring host institutes have the power and autonomy to screen and select the students best suited to their institutes.
- 4 Sending important student background information, such as their training, skills and goals to the host institute staff.
- 5 Clearly defining roles, responsibilities and expectations of host and visiting institute supervisors. Supervisors must also be compensated equitably between the institutes.
- 6 Inclusion and respect for host institute feedback for student evaluation and post-departure reflection activities.

It is important to be aware of the higher burden that these collaborative



activities place on the host institute staff, especially if they are not being compensated for their time. Equitable financing is a challenge that we are still working to overcome for the institutes involved in our study as we continue this collaboration. One of the potential options discussed in a joint focus group was to have the supervision role transferred completely to a host institute staff member, who could then receive the complete supervisor salary. However, this leads to two new challenges. First, the host staff member may not have the time to take over all of the supervisor's tasks. Second, there are often a diverse number of staff members involved in supervising students in different capacities, which can lead to conflict if only a single staff member is being compensated fully for their role. This is a situation that our partner in Suriname experienced, leading to them spreading the supervisor compensation across the hospital. As can be seen, overcoming financial inequity in building partnerships is no easy feat.

EQUITABLE RESEARCH FOR EQUITABLE PARTNERSHIPS

Those researching equity should reflect this value within their projects.^[8,9] One of the ways to conduct more equitable and ethical research is by including transdisciplinary research (TDR) methods.^[10] Global health practitioners often fail to collaborate with the people whom their research aims to help. The use of TDR in this study, such as the research team representing all involved institutes, helped to promote equity and local ownership of the project itself, improved the likelihood of the results leading to actionable and more immediate changes, and increased the relevance and success of the project in meeting the needs of those involved.^[11-13] We, as global health researchers, must realise that the ethical and equitable process of acquiring knowledge is just as important as the result.

CONCLUSIONS

Due to the globalisation of global health and medical education, HIC-based medical students are increasingly

completing medical electives in LMICs. While challenges remain, these should not render us inactive in our efforts to overcome them. There are a variety of steps that can be taken to tackle the inequities and unethical practices limiting the movement to decolonise global health. Building more equitable partnerships for international medical electives is not only possible but an essential standard that all those working in the field of global health and medicine should work toward reaching.



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Changing our language in global health: Inappropriate correctness or a powerful force driving epistemic justice?

It was 2018 when *OneWorld*, a Dutch online platform for journalism, published an article with the title *This is the colonial language we will no longer use* (translated from Dutch).^[1] The editing team argued that our language is peppered with (neo)colonial talk, condescension and above all the 'white Western perspective'. They also argued that journalists have an extra responsibility to decolonize language. To set an example in the Dutch media landscape, *OneWorld* announced they would no longer use a number of words, such as 'to empower', 'empowerment', 'ethnic', 'local', 'minorities' and 'developing countries'. They motivated their choices with an explanation for each word.

This extraordinary move was picked up by other media and other Dutch journalists. Columnist Asha ten Broeke wrote in *De Volkskrant* that *OneWorld's* initiative could lead to a positive outcome, as it would make people think about taken-for-granted norms.^[2] In the same newspaper, columnist Elma Drayer shared a different perspective. She wrote: "Of course, it would not hurt to take into account others' wishes and sensitivities when it comes to language use. But to think that reality will adapt to it is wishful thinking at best, and naïve at worst".^[3] In the meantime, the words banned by *OneWorld* were still widely used by other media outlets.

The words were also used by me, or at least one of them. In 2018 and 2019, I was writing a book about some of my PhD research results, through a Dutch publisher. It was different from my dissertation, because it was aimed specifically at the audience of Dutch people with an interest in working or studying in the Global South. So: no academic

language, no theoretical elaborations. It was meant to be practical and fun to read, while also insightful and eye-opening. I understood why 'developing countries' was on *OneWorld's* 'blacklist', and while they had suggested alternatives for each word on the list, there was not yet one for 'developing countries'. Despite *OneWorld's* arguments, I decided to use the term 'developing countries' anyway, mainly because I wanted my message to be received and embraced by my targeted audience. I did not want to be correct in language but ineffective overall because nobody would want to read the book. I even went as far as to title the book *The Third World On Your Resume*, to tickle or provoke my readers, and I made an effort to, again, explain my word choice in the book.

And now it is 2022. Would I still use 'developing countries' in my writings today? Absolutely not. So what has changed? In me, in Dutch society, in the world? I guess I am more aware of the powerful impact that words have on reality. Both in a good way, when the right words are used, but also in a bad way, when words are used that do not reflect or do justice to what the world is really like. 'Developed versus developing countries' is an outdated classification system, originating among multilateral institutions in the 1960s, for transfer of resources from rich to poor countries.^[4] It does not make people ask questions such as: What does it mean to be developed? How do we define potential? Or what do a developing and developed country have in common? Instead, people use the words to divide the world into two, in a way that perpetuates existing inequities. Unfortunately, the terms I use instead, such as low- and middle-income countries (LMICs), high-income countries (HICs), Global North and Global South, are controversial too, for similar and other reasons. Better alternatives are hard to find.

REASONS TO CHANGE LANGUAGE

My choice to write and speak differently today is related to the debate in The Netherlands about Zwarte Piet and whether this is an innocent Dutch tradition or a harmful event with roots in racism. It is also linked to the rise of the Black Lives Matter movement. George Floyd's murder in Minneapolis in the United States sparked large racial justice protests around the world.^[5] Additionally, my thinking and reasoning is linked to academic debates in global health. It is linked to questions such as: Is global health truly global? Who sets the agenda? Who is not heard? Numerous scholars have written and continue to write about this, such as Themrise Khan, Seye Abimbola, Catherine Kyobutungi and Madhukar Pai with their article *How we classify countries and people – and why it matters*. Chanel van Zyl, Marelise Badenhorst, Susan Hanekom and Martin Heine wrote a piece specifically about the term 'low-resource settings' which has recently gained ground in academic global health literature.^[6] The authors state that this term, as well as other proxies such as low- and middle-income countries, undermine the complexity of such settings and insinuate a level of homogeneity that is unsupported.

Lastly, my current language choices are based on developments, outside the field of global health, in the field of international development. In the Netherlands, we have Hucom, an awesome organization that works passionately towards equitable and fair humanitarian communication. Hucom's approach is to organize awareness events in the Netherlands, one of which is an annual award ceremony for both the best and worst campaigns by Netherlands-based NGOs that work internationally. Save the Children is a frequent nominee and winner of the award for the worst ad, with campaign videos that dehumanize



children by portraying them as skinny, sad and poor, without contextualizing the situation. Every year, Save the Children makes new videos and every year they end up being nominated by Hucom. In a television program about fundraising for international development, Pim Kraan, the director of Save The Children Netherlands explained why they continue to work this way: a campaign portraying positive images raises 200 euros a week, whereas a campaign saturated with negative images raises 9000 euro a week.^[7]

Hucom considers these simplistic and one-sided stories, produced by organizations working in international development – either through words or images – to actually be part of the problem these organizations are trying to solve. They state on their website: “We consider representation and discourse as integral to the production of the Global South and see the communication on (the needs of) developing nations and peoples by government, industry, NGOs and the media in the Global North as part of the problem of (the failure of) international development and worldwide issues of poverty, inequality and injustice”.^[8]

DOES LANGUAGE REFLECT OR SHAPE THE WORLD?

Elma Drayer was quick to write that it is naïve to think that reality is not affected by language because this process started long ago, and not in a fair way. Language is part of a (historically constructed) system that perpetuates the status quo and keeps powerful countries, institutions, organizations and individuals in power. My PhD research about power dynamics and relationships between international and Cameroonian staff in a hospital in Cameroon showed that many visiting health workers engage in ‘processes of othering’ in which they – deliberately or not – distance themselves (‘us’) from others (‘them’). I agree with the scholar Harng Lu Sin who states that this can “potentially create rifts that hinder the building of strong personal relationships”.^[9] In the inspiring TED Talk *The Danger of a Single Story*, the writer Chimamanda Ngozi Adichie shares some of her experiences with

such prejudice and the effect of one-sided and simplistic stories, created by people who do not see the full story, but rather what they want to see or think they see.^[10] It shows that we are not just bystanders of ‘the real world’. Through the things we see and the language we use, we actively shape and recreate it.

Processes of othering have greatly contributed to the fact that many people in the Global North do not look at people in the Global South as equals. It is widely known that feelings of superiority are not only associated with colonial and missionary medicine back in the days, but as much with the often short-term work of contemporary Global North health professionals in Global South medical settings.^[11] In 2012, Teju Cole wrote about the inability of many people in the Global North to look at developments in the Global South in a nuanced way, and with respect for the efforts of people in their own lives and their efforts to improve their country. Cole wrote: “His [American/European] good heart does not always allow him to think constellationally. He does not connect the dots or see the patterns of power behind the isolated disasters. All he sees are hungry mouths, and he [...] is putting food in those mouths as fast as he can”.^[12] It makes me think of a quote from Kofi, a Ghanaian school boy in Akusua Abb’s *Ashanti Boy*, written in 1959.^[13] I have read the quote many times, and I encourage all readers of this article to read it a few times to really get to the gravity of this boy’s message:

I want to do well in exams, because I want to... help everybody here. I must be a doctor, an engineer, or a lawyer to help. Now all the doctors, engineers and lawyers are Europeans, or nearly all of them, and they can't know us and our troubles as well as we know ourselves. There are not enough of them anyway, and they always go home in the end. They don't stay here. [Then, speaking to a European missionary:] We will get self-government one day. We will govern ourselves. Then we must have as good a government as you, and you must say 'These are good men, as good as us, so of course, their country will soon be as good as ours and then they will be our equals.'

What strikes me most is that the boy expresses his wish for himself and his people to be independent, to be able to run his home country of Ghana without European outsiders who come and go, while at the same time he shows a deep wish for the appreciation by these Europeans for being ‘as good’ as them, and therefore being equals. One day...

THE ROAD TO JUSTICE

The current visa problems in global health, hampering or even preventing travels of global health professionals from the Global South to travel to the Global North to participate in global health conferences, WHO and other meetings, are only one example that illustrates that we are far away from Kofi’s dream^[14]. Another example is the way media in the Global North reported during the Covid-19 pandemic; when it turned out that people on the African continent were not dying as massively as expected by many people in the Global North, media attributed this to a ‘miracle’ rather than to expertise and experience with fighting infectious disease, in combination with good leadership.^[15]

Adding up these insights leaves us with one important question: Based on the current academic and public debates about language in global health, how can we do better? First of all, let us closely look at our current language use. We cannot change our previous choices, but we can reflect upon these choices based on what we know now. Jurriën Hamer, a Dutch philosopher and lawyer, even recently wrote: “Out of fear of admitting having made the wrong choices [he refers to eating meat and flying around the world], people do not acknowledge their role in the world, and the effect of their behaviour. Society as a whole is paying the price for that”. Hamer also argues that people can reap the benefits from the sober realization that everyone makes mistakes: “We want to see our value reflected in the eyes of others. We want others to be proud of us”.^[16] In this light, in the context of this human wish to be seen and acknowledged for the efforts made, I think it is even more harmful to continue with language that takes away space for others – people with the same desire

but less agency – to be seen, heard and acknowledged. For their full capacity.

So what is the best way forward? What terms should be avoided? Of course, there is not one answer to that. Themrise Khan and colleagues argue, in the earlier mentioned article, that people could be more specific about the terms they use. For instance, when using ‘low-resource setting’, an explanation can be provided as to *why* and *how* a setting is low-resource and along which dimension(s). They also argue that changing language alone is not enough; it should also be about changing intentions, methodologies and practices. This is in line with what Himani Bhakuni and Seye Abimbola argue in their article on epistemic injustice in academic global health; that it is about practices related to knowledge production, use and circulation.^[17]

So, does Elma Drayer have a point in saying that societal change through language is wishful thinking? Language is only one aspect of the power system, but as said, it does contribute to the construction of the world we all live in. People need be aware of this in order to use the power of language for the better. In order to learn more, I argue that people in the field of global health can also learn from organizations in other fields, such as *OneWorld* in journalism, Hucom and also Partos in international development. Partos is the Dutch membership body for (more than 100) organizations working in international development, and their Dream Paper *Shift the Power* is highly recommended.^[18] Another document worth mentioning is Hucom’s most recent Communication Code.^[19] The concrete recommendations for ethical communication, linked to dignity, context and nuance, can be applied to the field of global health too. At the very least, using these lessons in the field of global health – in practice, research and education – contributes to open and equitable relationships on both an individual and institutional level. At the very best, it paves the way to justice.



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Dream paper:
Shift the Power

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How decolonising global health will improve lived experiences in the Global South

Last year, several African co-authors and I submitted a manuscript to one of the leading scientific journals. We received comments from the reviewers, one of which read,

“It seems that the authors, as well as the people of Africa, may need “balanced” education in the food and health continuum.”

I found this comment deeply offensive, but because I thought I was overreacting, I reached out to the lead author – a Ghanaian professor. He was even more livid. We both concluded that this reviewer’s microaggression was yet another manifestation of a colonial mindset in academia.

Our experience is not unique. Samson Kaunga Ndanyi, a Kenyan historian and author, once tweeted,

“A reviewer rejected my paper coz it ignored “leading voices” in the field. All the “leading voices” they meant were Europeans and Americans. I used leading voices/authors from Africa.”

While experiences like these might seem trivial, I believe that they reflect deeply entrenched power asymmetries in global knowledge systems. The field of global health is particularly plagued by power imbalances between the Global North on the one hand, and the Global South on the other. These power imbalances manifest in various ways including epistemic injustice, saviourism, white privilege, racism, foreign gaze – to mention a few. Collectively, these manifestations have triggered calls for “decolonising global health”.^[1,2]

However, not everyone agrees with the appropriateness of the term “decolonisation”. On one hand, there are those like Madhu Pai, a Professor of Global Health at McGill University, who welcomes the calls to decolonize global health because,

“...it shows some awareness about lack of diversity in global health organizations, the power asymmetry that is all pervasive in global health... and the many contradictions within global health.”^[3]

In contrast, Themrise Khan, an international development expert from Pakistan strongly opposes the use of the term “decolonisation”. She argues that decolonization is fast becoming a “comfortable buzzword for the aid sector”.^[4]

I am comfortable with the term “decolonisation” because in just one word it communicates the uneven power dynamic between colonizers and the colonized, and it implies the possibility of disrupting this dynamic. Therefore, I co-founded the Global Health Decolonization Movement in Africa (GHDM-Africa). Our mission is to contribute to decolonizing global health by mobilizing a critical mass of African voices to speak out about what we perceive as the manifestations of colonialism in global health.

In our inaugural publication, ‘Pragmatic Approaches to Decolonising Global Health in Africa’, we make recommendations targeting various stakeholders in global health.^[5] For example, we ask global health funders, most of which are domiciled in the Global North, not to fund “parachute” research proposals — that is, proposals that were conceptualised by Global North researchers for implementation in Africa without significant intellectual contribution from their African counterparts.

Our publication is one of several in the literature that propose practical recommendations for addressing power imbalances in global health.^[6,7] However, the existing literature falls short of articulating tangible benefits that might arise from the decolonization of global health. It is easy to fall into a trap of thinking about decolonization as an abstract concept without giving much thought

to those whose lived experiences will benefit from decolonizing global health.

To contribute to filling this gap, I reached out to a few of my African colleagues to get their perspectives.

Here is what they said.

DIVERSE SOURCES OF KNOWLEDGE WILL BE VALUED

In global health, sources of knowledge in the Global North are generally considered superior to other sources. This reflects the epistemic injustice that is pervasive within academia.^[8] In a world where global health is decolonised, Ngozi Erondu, a Nigerian-American infectious disease epidemiologist says,

“I would apply for fellowship positions in the Philippines and take a course on epidemiology in Uganda and watch an online lecture about Tongan social scientists validating an innovative community integration approach to food security resilience in the midst of climate change.”

By embracing diverse sources of knowledge, Ngozi believes that her professional experience will be much more enriched.

LOCAL COMMUNITIES WILL HAVE INCREASED ACCOUNTABILITY

One major criticism of global health, and international development in general, is the lack of accountability to local communities. Emilié-Koum Besson, a health finance specialist from Cameroon believes that this would not be the case in a world that is truly decolonised,

“We would stop seeing people as “beneficiaries” and using terms like “developing” and “underdeveloped” which are rooted in stereotypes and colonial inherited binaries. Then, the work would really be global, meaning that the flow of ideas and actions would be multidirectional, and the accountability would really be to the communities.”



In other words, global health would be informed by the lived experiences of communities and their expressed needs rather than based on priorities created for them and without them by practitioners mostly in the Global North.

THERE WILL BE FREEDOM TO DETERMINE LOCAL PRIORITIES

Global health programs often reflect the priorities of funders and influential policymakers in the Global North, and these priorities are not always aligned with the needs of the Global South. Jabulani Ncayiyana, a South African epidemiologist believes that decolonising global health will give him freedom to respond to local needs,

“This freedom will impact my work positively... as a Global South practitioner, I can set the agenda and priority for global health research in my setting, rather than follow a Global North imposed agenda and priority for global health research.”

Samuel Muhula, an impact evaluation expert from Kenya agrees,

“...This will be different from what is happening now where donors from Global North define the issues they would like to fund in form of a call for proposals. Africa will be in a better position in solving its health problems than ever before.”

GLOBAL SOUTH INSTITUTIONS WILL BE STRENGTHENED

The political economy of international development funding hinders the effectiveness and sustainability of local organisations, as well as their ability to build capacity and scale^[9]. This is because funders often channel funds meant for program or initiatives in the Global South through more established organisations that are headquartered in the Global North. This situation perpetuates the dependency of Global South organisations on their counterparts in the Global North.

Jeanine Condo, a Rwandan medical doctor and associate professor of public health says that this dependency can be disrupted if funders changed their policies,

“We need funders to invest more in strengthening local organisations by giving them grant conditions that are comparable to those in Western countries. For example, the US Government could make it easier for African institutions to be eligible for Negotiated Indirect Cost Rate Agreement. Many funders limit indirect costs to levels that are so low that it is impossible for African institutions to grow sustainably.”

CONCLUSION

The calls for decolonising global health are going to get louder. However, there is a risk that, like Themrise Khan wrote, decolonisation simply becomes another buzzword and that we forget that there are real people whose lived experiences continue to be negatively impacted by the power imbalances in global health. I have attempted to identify some real-world benefits of decolonising global health. Yet, my attempt is anecdotal at best and does not go far enough. It does not capture the voices of other stakeholders in the Global South such as policymakers or patients living in the disadvantaged communities where global health programs are often implemented. Neither does it capture the voices of practitioners in the Global North whose experiences are likely to be enriched by more equitable partnerships. Nevertheless, I am certain that a world in which global health is decolonised will be a better world for everyone.



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It's time to speak up to our retirement funds!

An extra perspective on sustainable health

In December 2021, MTb published the edition *Climate Changemakers in Health*. This edition focused on how to address the urgency of climate change as a medical professional. In addition to this, MTb presented several case studies in the health sector that show actions and experiences on how to reduce the carbon footprint. Awareness is growing, and more and more hospitals and other health care institutions employ sustainability advisors and set up Green Teams in order to achieve positive impacts in their daily work environment. Moreover, sustainability is included in the Dutch Integral Health Agreement (Integraal Zorgakkoord) and the government stimulates continuation of the Green Deal 3.0.

It is inspiring and hopeful to see this rapidly growing movement amongst health care workers. Indeed, according to the recently updated Dutch code of conduct for physicians, physicians are obliged to promote health and have to be aware of the dependent relationship between health, climate and environment. Therefore, we, medical professionals, have to reduce our own ecological footprint by changing our medical routines.

From this point of view, we think it is crucial to add an extra perspective on our way towards sustainability. This potential could come from an unexpected area, with an unexpected high impact: the retirement funds. After all, the sustainability potential of our society depends largely on investments of big capital. All Dutch retirement funds together invest about 1500 billion euros. Unfortunately, those funds focus traditionally on maximum efficiency of their investments, and not on the habitability of our earth. To date, the lion's share of these investments still finance the climate crisis by funding the fossil fuel industry, other big industrial polluters, massive deforestation, and even the arms industry.

In recent years, members of retirement funds (as well as clients of banks and insurance companies) are more and more aware of these investments. Indeed, personal efforts for an eco-friendlier lifestyle feel futile when our own money is spent contra-effectively by these funds. In fact, increasing social pressure has already made some large investors change their course. For example, retirement fund ABP is finally withdrawing its investments in fossil fuels in 2023. Unfortunately, most people are not able to choose their retirement fund. However, the retirement funds are legally obliged to respond to your concerns. So you could start by sending them an email and sharing your opinion. Or you can choose to speak up on social media, often an effective way to contribute to social awareness in order to achieve change. It is our money, our health and our future. Make the first small step to move this enormous amount of money towards sustainable investments. Send a message to *Groen Pensioen* (<https://groen-pensioen.nl>) or attend one of their webinars where you will get tips and tricks on how to speak up to your retirement fund. Even a prepared letter, ready to be sent to your retirement fund, is waiting for you.

Investing money from medical professionals in a health-damaging fashion is simply unacceptable. Promote health by taking responsibility for these investments, stand up to your retirement funds, and demand a radical change towards sustainable investments.



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Planetary health: shaping the future of planetary health – equitable and sustainable global health



After 16 years, the European Congress on Tropical Medicine and International Health (ECTMIH) is returning to the Netherlands. In November 2023, the Netherlands Society for TMIH and its partners will host the 13th edition of this European Congress. The overarching theme will be PLANETARY HEALTH, which has grown in importance, as increasingly – and at an unprecedented pace – we are living the impact of our collective activities on human health and on the planet's ecosystems. So the congress is more than timely, and we aim for a deeper understanding of the interconnectedness of human health, climate change and disrupted ecosystems, and for proposed solutions to urgent problems. The congress intends to offer a platform for dissemination of new insights and for presenting interdisciplinary approaches to global health problems.

We invite researchers from all parts of the globe to present their latest research in all domains of global health, including infectious and tropical diseases and sexual and reproductive health and rights, to name a few. (see Box 2). We encourage participants to address underlying social, cultural and economic dimensions of health, and to build on the principles of universal access to health, equity and human rights. We will adopt a cross-cutting and interdisciplinary perspective to tackling health problems in the 21st century. The congress is planned for Monday to Thursday, 20 to 23 November 2023, and

will be held at the contemporary music complex Tivoli Vredenburg in Utrecht.

BOX 1: SHIFT IN FOCUS

The Amsterdam congress in 2007 was among the first to include the several dimensions of health in the programme, and actively support establishing partnerships and networking to improve health globally, as reflected in the title of the congress 'Partnership and Innovation in Global Health'. This trend of widening the focus was also seen in the congresses that followed – such as the inclusion of an equity and human rights lens, and addressing the consequences of migration on health, among others in the congresses in Verona (2009), Barcelona (2011), and Bergen (2021). The 10th edition in Antwerp (2017; 'Health in (r)evolution. Environment – migration – technology – empowerment') specifically aimed to "provide a forum for reflection on the role and position of tropical medicine, global health and international cooperation in the 21st century, taking into consideration disruptive changes such as human migration, environmental evolution, technological innovation and political power shifts."

BOX 2: PROGRAMME FOCUS AND TRACKS

With the 2023 congress, we emphasise the importance of health equity and universal health coverage to ensure that all populations – and especially those in low(er) resource settings – have optimal chances of health and wellbeing. As such, we expect ECTMIH 2023 to catalyse the transition and change we need for equitable, just, and sustainable societies. We will build on global health traditions to emphasize the importance of health equity and universal health coverage to ensure that all populations – and especially those in low(er) resource settings – have optimal chances of health and wellbeing. With this in mind, ECTMIH2023 will:

- act as a catalyst in the transition and change we need to achieve equitable, just, and sustainable societies
- encourage the active participation of researchers from low- and middle-income countries, global thinkers, policy and decision makers
- stimulate debate on the role of cooperation agencies and of scientific institutes in all areas of global health

The tracks and cross-cutting topics:

1. Planetary health and health systems;
2. Infectious Disease and Neglected Tropical Diseases;
3. Non-communicable Diseases;
4. Mental Health;
5. Sexual and Reproductive Health and Rights;
6. Child and Adolescent Health.

Cross cutting topics in each of the tracks are (a) Prevention, diagnoses, treatment and care; (b) Public health, community health, primary care, inpatient care; (c) Universal health coverage and health equity; and (d) Health policy.

BOX 3: DELEGATE PROFILES

We encourage the active participation of researchers, global thinkers, and policy and decision makers in the programme, and the inclusion of debates on the role of cooperation agencies and of scientific institutes in the field of global health. Although ECTMIH is a European congress, delegates from all over the world, in particular from LMICs, are invited to contribute and/or to participate. A disparate mix of international health professionals and researchers, from the various branches active in global health, both in the North and South, will gather at this congress:

- Academia: researchers and undergraduate, graduate and post-doctoral students
- Professionals in the healthcare system: health specialists, physicians, nurses and other health workers, global health experts
- Professionals from governmental agencies: health ministries, regulatory bodies, health departments; and from non-governmental organisations
- Representatives from private research & development organisations

INVITATION TO PARTICIPATE

We invite the NVTG Working Groups and others interested in planetary and global health to mark the date, and engage with us over the next months in the shaping of the congress. The call for proposals for organised sessions in any of the six tracks is open from 15th of November 2022 until 31 January 2023, and the call for proposals to submit abstracts will open on 1 February 2023. On our website (<https://www.ectmih2023.nl>) you will find regular updates on the programme, enabling you to become part of the global and planetary health network.

BOX 4: ORGANISING PARTIES: UMCU, FESTMIH, NVTG, KCGH

The congress is organised by the European and Dutch Societies for Global Health and Tropical Medicine (FESTMIH, NVTG), the Knowledge Center Global Health (KCGH), and the University Medical Center Utrecht.

UMC Utrecht: a leading international university medical centre generating, testing, sharing, and applying knowledge on health, illness, and health care for the benefit of patients and society. With approximately 12,000 employees, the University Medical Center Utrecht is one of the largest public health care institutions in the Netherlands and the largest employer in the region. Physicians, researchers, and graduate students work together to find solutions for a wide range of major medical issues. UMC Utrecht aims to play a major role on the international research stage and to play a leading role in research and innovation.



FESTMIH, the Federation of Societies for Tropical Medicine and Global Health, is a European network promoting research and training in tropical medicine and global health, aiming to connect civil society, research and medical institutions to develop strong alliances and policies on Global Health. The network was founded in 1994 in the build-up to the first European Congress on Tropical Medicine and International Health in Hamburg one year later. FESTMIH's mission is to improve the health status of people worldwide by establishing partnerships and mobilising professionals and by promoting and disseminating research in global health and tropical medicine. Activities of the network include: the organisation of European Congresses (since 1995 we co-organised twelve ECTMIHs throughout Europe) and of other scientific meetings at European and international congresses; the publication of the Journal Tropical Medicine and International Health; liaising with European schools of global health and tropical medicine; and advocating for universal access to health and equity in health. Meet the network and our members on the FESTMIH website (www.festmih.eu).

NVTG, the Netherlands Society



for Tropical Medicine and International Health, founded in 1907 – brings together global health professionals and students. Strategic goals of the NVTG are networking, education, science and advocacy for improved health globally and universal access to health. The backbone of the NVTG is its working groups, who combine active collaboration with partners globally with scientific research and networking in all domains of global health. Through our annual conference, global health film festival, and our journal, we provide space for connection and collaboration on topical issues in global health. In addition, we realise our mission through the promotion and support of scientific research and dissemination of knowledge in all thematic areas of global health. Since the 1960s, the NVTG, through its sister organisation OIGT, offers a comprehensive post-graduate training programme for MDs (MD Global Health and Tropical Medicine), and supports vocational training. In collaboration with our partners, we advocate among policy makers and the public for social justice & health equity and universal health. Read more on the NVTG website (www.nvtg.org).



KCGH: Global health is about improving health and reducing health inequalities for all people worldwide, through education, research and practice. The Knowledge Center Global Health (KCGH) supports knowledge exchange in the field of global health. We do this by connecting healthcare and global health professionals, making global health knowledge more accessible, learning from it, and thereby promoting its application in Dutch healthcare. KCGH connect experts, organizations and healthcare providers around current themes in global health, with a focus on planetary health and health equity in the coming years. We are also committed to bringing global health issues to the attention of a wider audience. See KCGH website (www.kcgh.nl).



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Meet the ECTMIH2023 team on www.ectmih2023.nl/pages/committees





Making health justice happen – step up or step aside

This article is written as an introduction to the side event Wemos organises during the 'Decolonizing Global Health' symposium on the 24th of November 2022.

DISCUSSIONS LEADING TO ACTIONS

The only valid reason to discuss decolonization of global health is if it leads to action to address root causes of (health) inequity and injustice, and by doing so leads to health for all. The global health community – NGOs, academia, social movements, trade unions, religious organisations, interest groups, diaspora, media, and cultural organisations – are key in pushing for systemic change in the global health architecture. But before we do, we need to recognize the power dynamics, reflect on our own role in this, and be willing to radically change our way of working.

THE NEED TO CHALLENGE THE STATUS QUO

More than half a century after most colonized countries reclaimed their independence, the concept of decolonization has become mainstream. Academia, civil society, donors, and global health institutions across the globe have embraced the topic in an ever-growing body of publications, webinars, and symposiums. There is general agreement that colonialism has impacted health definitions, health theories and research, health systems and health practices. . . . Some authors have even gone as far as to say that “...public health is an apparatus of coloniality that manages (as a profession) and maintains (as an academic enterprise) global health inequity.”

As the call to action grows, so does the doubt about the intention to act. Thought leaders from the global South have accused the global North of setting and co-opting the decolonisation agenda with no or limited platforms for the global South. Donors speak of wanting

to ‘shift power to the South’ and try to do so through community participation or so-called country ownership. But they maintain their rigid reporting requirements and exclusive decision-making processes. And while much of global Northern civil society is doing penance for its ‘white gaze’ and ‘white saviourism’, it is often not challenging the status quo. As Samuel Oji Oti at the recent KIT Power of Knowledge Congress put it: “*In the past colonised people were subjugated by guns, now by emails, zoom calls, and grant proposals.*”

THREE CRITICAL QUESTIONS

Collectively we must do better to make health justice happen. Letting go of power and position is painful and scary. But as many social movements have shown, it is possible to correct power imbalances. So, let us start with asking ourselves three critical questions: 1) what is our added value, 2) what is our relevance, and 3) what is our legitimacy in the global health arena? Is our work improving and adding value to the critical global health issues? Is our work relevant, i.e., useful for or related to issues identified by those who are most affected by health inequity and injustice? Is our work justifiable and defensible, i.e., do we have legitimacy to speak and act on the issue?

For Wemos, the answers to these questions are shaping our future strategy. According to our stakeholder consultation, we have relevant expertise in global health and address the key structural barriers to health equity and justice. But we could be less cautious in speaking out, act faster, and be more willing to risk our own position. We translate complex information to understandable products and messages, and work to open global spaces for others. But we need to ground our propositional global lobby more in country realities and place national organisations at the centre of our work. We use leverage and connections to change existing narratives,

processes, and policies. But we could do more to challenge the status quo instead of working within existing systems.

STEPPING UP OR STEPPING ASIDE

Where you stand depends on where you sit. So be prepared to solicit input from ‘unusual suspects’ to get raw, honest feedback, in anonymised form if needed. Acting on this input is the challenge as difficulties are often in the details. Which and whose ‘country realities’ and ‘narratives’ are we talking about? What changes are needed in our human resources policies and practices? How do we create equal partnerships? How do we – both from global North and global South - hold each other accountable? In other words, how do we make this happen?

Decolonization is an active, iterative, and continuous process, not just an intellectual exercise. It entails concerted effort by both global Northern as well the global Southern actors across sectors. It means stepping up to a new reality or stepping aside if no longer needed.

BOX 1: WEMOS

Wemos is a global health advocacy organisation based in the Netherlands. Our mission is to advocate structural change to realise global health justice. We were founded 43 years ago by a group of Dutch medical students who believed that medical interventions in low- and middle-income countries (LMICs) can only be effective if the underlying causes of health problems are addressed. Some of these former students are still a member of the NVTG! Since our early beginnings, we have acquired an international reputation for our rights-based and systemic approach to health. We target policymakers and politicians, but also reach

out to the public at large. As part of our strategy revision, we commissioned a literature scan of African perspectives on decolonization within global health as well as a stakeholder consultation in the Global South and Global North on the added value, relevance, and legitimacy of our work. This gave us a lot of food for thought and action around this topic. Join us at the side event at the annual NVTG Symposium on decolonizing global health, to share and debate these lessons. We will use interactive case studies to make it real, and hopefully leave you with perspectives and thoughts for your own work.



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6. The Power of Knowledge - KIT Royal Tropical Institute
7. 9 powerful social change movements you need to know about - Amnesty International Australia

A child with extremely dry skin

SETTING

This case is from Mongo, the capital of the Guera province, in the south of Chad. A team is working here for the national Leprosy programme where patients with skin problems present for diagnosis and treatment. Some people come for a first consultation, but often patients have already been treated elsewhere without success and come for a second opinion. Referral is possible, but local doctors often prescribe expensive medication that may or may not be indicated. Consultation by a specialized dermatologist means referral to the capital N'Djamena, 520 kilometres away.

CASE

A seven-year-old boy is presented by his parents for consultation. He has extremely dry skin that feels very firm and shows a scale-like structure over almost the whole body (see figure 1,2). The tight skin has formed an ectropion of both lower eyelids. He has had this from a young age, but it is unknown exactly for how long. One of his siblings has the same problem, but it is unknown if this is a brother or sister. His parents feel that he is not growing well. The child makes a sad impression. The parents are very worried about him and have been to different clinics/hospitals without a satisfactory result.

SPECIALIST ADVICE

The dermatologists of the Consult Online panel diagnosed this as a form of ichthyosis, with a differential diagnosis of ichthyosis vulgaris and X-linked ichthyosis. The possible growth retardation could not be explained.

The specialists' advice was to try and differentiate between the different forms of ichthyosis. This can be done by taking a broad (family) history to understand possible inheritance patterns or consanguinity, to exclude the condition as a possible syndromal sign (e.g. malignancy, see below), and understand the start and development of the disease from birth. Next to this, it is helpful to inspect the skin fully and describe the affected areas since this might also differentiate between different forms of ichthyosis. Making a definitive diagnosis makes it easier to predict inheritance and make a better assessment of the course of the disease.

GENERAL CONSIDERATIONS FOR MANAGEMENT

There is no cure for this condition, but symptoms can be treated. Treatment for both forms of ichthyosis is quite similar: taking baths with a bit of salt or bath oil on a regular basis. The skin needs to be kept oily by salving it multiple times a



day with an emollient (oily ointment) or ureum on an oily base. Salicylic acid creams should not be used on the whole body, because of risk of systemic side-effects. Severe cases can be treated with systemic retinoids (acitretin or isotretinoin) but this is often not possible in a low-income setting. Additional extra-cutaneous manifestations should be treated. It is difficult to predict the effect of treatment but (some) improvement of skin and mucous membranes is possible over time. It is important to address the psychological impact of this disease. Counseling of possible pregnant carriers should be considered (see below).

ICHTHYOSIS

An average adult has a skin surface of approximately 1.8 m². The skin protects the body from influences of the external environment and is anatomically divided in three layers. The epidermis is the upper part and consists mainly of keratinocytes formed in the basal layer (stratum basale). The keratinocytes migrate upwards and undergo a complicated cornification process involving different enzymes and proteins before they form the outer (dead) part of the skin, the stratum corneum. Melanocytes, that form the melanin that pigments the skin, are also part of the epidermis.^[1,2] The middle part is the dermis, consisting mainly of collagen, elastic tissue, vasculature (blood/lymphatic fluid), nerves for proprioception, pain and thermoregulation, hair follicles and glands.^[1] The third layer called subcutis consists mostly of fatty tissue for isolation.^[1]

Ichthyoses are a group of skin abnormalities, caused by cornification disorders, that lead to generalized scaling of the skin.^[2,3] The severity of this scaling can vary among patients.^[2] The majority of ichthyoses are inheritable; these can be divided in syndromal forms (affects skin and other organs) and non-syndromal forms (only cutaneous manifestations). The non-syndromal forms can be divided into common (ichthyosis vulgaris and X-linked ichthyosis) and uncommon forms (autosomal recessive congenital ichthyosis and other forms).^[3] The heritable forms originate from mutations in different genes that encode for proteins and

enzymes involved in skin development and function.^[2] These mutations can lead to hyperplasia of the epidermis, thickening of the stratum corneum, increased desquamation and a scale-like structure of the skin, the result being a malfunctional skin barrier.^[2,4]

Although most ichthyoses are inheritable, acquired forms do exist due to nutritional deficiencies, infections, autoimmune or malignant diseases.^[2]

ICHTHYOSIS VULGARIS

Ichthyosis vulgaris is worldwide the most common form of ichthyosis, with a prevalence in the literature varying from 1:100 to 1:250 births.^[2,3] Prevalence is worldwide but seems highest in Europe compared to Asia or even African Americans (lowest).^[5]

The underlying cause is a loss-of-function mutation in the filaggrin-gene leading to abnormal cornification and trans epidermal loss of water.^[3,4] Its inheritance pattern is autosomal ‘semi’ dominant, with incomplete penetrance. Individuals with the mutation on one allele (heterozygotes) show mild to moderate symptoms, whilst individuals with the mutation on both alleles (homozygotes) show moderate to severe symptoms.^[2,3]



Figure 1



Figure 2

Symptoms start in the first months or years of life^[3] and include dry skin with fine white-greyish scaling on the extensor surface of extremities

TABLE 1^[2]

HERITABLE	
SYNDROMAL FORMS (CUTANEOUS + OTHER ORGANS)	NON-SYNDROMAL FORMS (ONLY CUTANEOUS)
<ul style="list-style-type: none"> · Contiguous gene syndromes · X linked dominant disorders · With hair abnormalities · With neurologic involvement · With other associated symptoms 	<p>Common</p> <ul style="list-style-type: none"> · Ichthyosis vulgaris (1:250*) · X-linked recessive ichthyosis** (1:6000*) <p>Uncommon</p> <ul style="list-style-type: none"> · Autosomal recessive congenital ichthyosis (1:200,000*) <ul style="list-style-type: none"> – lamellar ichthyosis – congenital ichthyosiform erythroderma – harlequin ichthyosis · Keratinopathic ichthyoses · Other forms
ACQUIRED	
<ul style="list-style-type: none"> · Nutritional deficiencies · Infections · Auto-immune · Malignancies 	

* incidence in number of births

** can present as syndromic and non-syndromic^[7]

and abdomen. The flexures and face are often not affected. In addition, there can be keratosis pilaris and hyperlinearity of the palms and soles. Symptoms tend to increase in dry and cold weather and decrease in hot, sunny and humid weather. It is strongly associated with atopy (eczema, asthma, and hay fever).^[2,3]

X-LINKED RECESSIVE ICHTHYOSIS

X-linked (recessive) ichthyosis is the second most common form of ichthyosis worldwide, with a prevalence in the literature varying from 1:4000 to 1:6000 male births.^[2,3] Prevalence is worldwide and equally distributed among ethnic groups, almost exclusively in males.^[6] The condition is genetically transferred by an often asymptomatic female carrier that passes on a mutated X-chromosome to her male child, who will express symptoms of the disease.^[3] The condition is caused by a mutation of the STS gene on the X-chromosome. This causes a steroid sulfatase deficiency and leads to abnormal cornification through different pathways.^[2,3] In carrier females pregnant with a child with X-linked recessive ichthyosis, a steroid sulfatase deficiency in the foetal placenta leads to low or absent oestrogen levels in the intrauterine (urine and amniotic fluid) environment. This can cause insufficient cervical dilatation and decreased response to oxytocin. This may lead to serious obstetric complications such as prolonged or obstructed labour and the necessity of a caesarean section.^[3,7]

Symptoms of X-linked recessive ichthyosis often start in the neonatal period with a systemic peeling of the skin and evolves within years into fine scaling and later on generalized, symmetrical, often dark brown adherent squama on the trunk, scalp, extremities, axillae, lateral parts of the face and especially the neck. Sparing can be seen in the popliteal and antecubital fossa, hand palms and foot soles and the central part of the face.^[2,3,7] The affected area can itch.^[7] This type of ichthyosis can also present as a syndromal form with extra cutaneous manifestations which include corneal opacities (that can also be seen in asymptomatic carriers), attention deficit hyperactivity

disorder (ADHD), epilepsy and an increased risk of cryptorchidism.^[2,3,7]

DIFFERENTIAL DIAGNOSIS

Differentiating between these two forms of ichthyosis seems relevant to predict inheritance patterns, counsel possible carriers before or during pregnancy, and treat associated extracutaneous manifestations.

Often however, ichthyosis vulgaris and X-linked (recessive) ichthyosis are clinically indistinguishable because both forms show variations in symptoms.^[3,7] As also advised by our specialists, it could be helpful to look at the pattern and colour of skin manifestations, obtain information about the onset and progression of the disease over time, including any problems during labour, ask for extracutaneous manifestations, and look for an inheritance pattern in the family history. Genetic testing could be performed for a more definitive diagnosis, this however is often impossible in a low-resource setting.^[2,4]

FOLLOW-UP

The patient was prescribed an oily ointment (unscented Vaseline) to be used after soaking the skin in a bath. The patient was not seen again after this.

On review of the case while writing this report, his facial features and the large tongue are suggestive of Down's syndrome. This condition is associated with ichthyosis vulgaris and may also explain the growth retardation.



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Mama's HeART project

Empowering and supporting guardians of children with chronic illness and/or disability in the Nkhoma Mission Hospital catchment area, Malawi

BACKGROUND AND RATIONALE

Malawi is one of the poorest countries in the world. [1] In this low-income setting, with insufficient capacity in health and social support systems, children with chronic illness and/or disability are more disadvantaged and at higher risk of marginalization, malnutrition and dying at an earlier age. [2,3]

Though there is little data available, the 2015-16 Malawi Demographic and Health Survey reports that 29% of children between the ages of 2 and 9, and 16.5% of children between the ages of 5 and 17 have at least one specific functional problem or disability. [4]

Nkhoma Mission Hospital (NMH) is a rurally located 250-bed district hospital in southern Malawi, serving a large catchment area. It is unknown how many children with chronic illness and/or disability live in this area. NMH staff noted that informal caregivers (guardians) of these children are struggling to give them the necessary care. It was apparent that many children had not been attending follow-up clinics on a regular basis. A questionnaire conducted amongst staff suggested families of these children are more disadvantaged due to extra financial, physical and mental challenges. The overall increased burden of caring for these children falls mainly on women, who are insufficiently prepared for this role and have to meet the medical needs of their chronically ill child as well as taking care of routine household chores and providing other basic needs for the family. [5,6]

It is known that empowering and educating guardians will directly benefit the child. Studies show that the delivery of psychosocial interventions by non-specialist providers (such as guardians) may improve the child's behavioural

and developmental outcomes. [7] Unfortunately, there are no sustainable financial or educational programmes from NMH supporting these guardians.

AIM

To perform a situational analysis that explores the financial, physical and emotional challenges guardians face when caring for their chronically ill and/or disabled child.

METHODS

A guardian was defined as a family member, relative or friend who was recognised as taking the main burden for the caring responsibility of the child at the household level. [8] Guardians of children with a disability and/or chronic illness attending the paediatric outpatient clinic or admitted to the paediatric ward were eligible for enrolment in the study. A cross-sectional survey was done using a locally designed questionnaire and semi-structured interview.

RESULTS

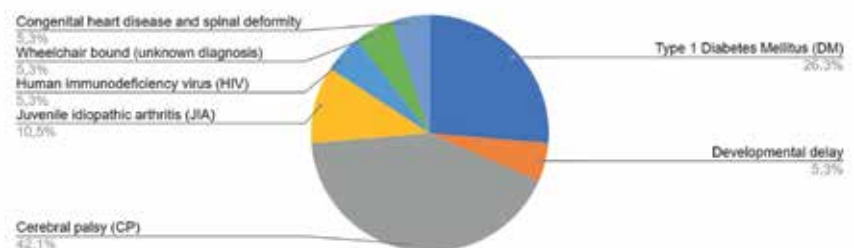
A total of 19 children and their guardians were enrolled. Of these, 80% were the mother of the child and a further 10% the grandmother. Almost all reported earning money by farming or informal piecework. The overall chronic conditions and/or disabilities of the children are presented in graph 1.

DIAGNOSIS AND PROGNOSIS

Overall knowledge regarding the diagnosed disease of the child was poor, with 30% of guardians reporting to know little to nothing about the disease. Regarding prognosis of the condition, knowledge was limited to a few. Guardians of children with diabetes mentioned the importance of a healthy diet and dietary restrictions. On the other hand, those with CP children knew little about the prognosis and mainly reported worries about their child not being able to go to school.

CHALLENGES FACED AND SUPPORT RECEIVED IN CARING FOR THE CHILD

All participants reported facing financial challenges, expressed in: lack of food for the child and themselves, lack of clothes, soap and/or shelter, not being able to buy (already subsidised) fertiliser and lack of transport money to the hospital. Multiple guardians reported being single or divorced, causing even more financial strain on the sole caretaker. Several guardians had difficulties in finding work, doing business or working on the farm due to the demanding care for the child. Interestingly, in response to the open-ended question of what challenges are faced when caring for the child, no guardians reported having any emotional or psychological challenges.



Graph 1. Chronic conditions and/or disabilities of included children



PHOTO CREDIT: HANNEKE DE VRIES

UNMET NEEDS

When asked about non-financial support they would like to receive most, guardians most mentioned food, blankets, clothes and shelter (renovation). More than half the guardians of children with CP would like to receive something to help carry their child; two guardians would like help getting their child into school, and three other guardians would like to receive training in farming or rearing livestock to generate income.

Although no guardians initially mentioned the need for emotional or psychological support, all 19 reported being interested in meeting other guardians with children in a similar situation to “encourage one another”, “thereby reducing stress and worries”. This unmet need was further supported when asked what guardians would want if a project was to start, mentioning “women should share knowledge”, “teaching each other how to care for sick children”. “We should be united” and “learn from each other on how to do business”.

Furthermore, all guardians reported that more information about the child’s condition would be beneficial: to “learn new things about the child’s condition” and that “life could only change for the better” as “we feel things were not well explained to us”. In addition, all guardians wanted to receive information regarding hygiene practices, to “prevent disease” and “take better care of the child.”

DISCUSSION

Due to the lack of well-developed health care and social welfare services, Nkhoma, like other places in Malawi, depends on informal caregiving to provide support for its chronically ill and/or disabled children. Most of the participants with this role were female and the mother of the child. This gendered labour division is due to the well-established cultural and societal norms of gender roles and expectations in the Malawian context. Moreover, mothers feel that this caring responsibility cannot be left to anyone else, as they view the task as ‘inherently

theirs’.^[8] In our study, poverty was so serious it was the main issue raised by all participants. Consequently, the main challenges faced in the everyday care of their child were basic challenges, such as obtaining enough food or having adequate shelter. It was noted that most children with CP had chronic malnutrition and that guardians of children with diabetes highlighted the importance of adequate food intake, while also mentioning difficulties in finding food. Nutritional support would be especially useful for these subgroups.^[2,9]

The demanding full-time caregiver responsibilities, confining a guardian to their home to take care of the child, are coupled with difficulties in accomplishing economic responsibilities. The time contributed to providing care thus creates a major time burden, exacerbating poverty amongst already previously poor caregivers.^[10,11] Furthermore, the financial support received was non-existent or highly unreliable, exacerbated by many caretakers being widowed or single without an independent income. Multiple guardians reported that the extent of impoverishment directly influenced their health-seeking behaviour. Assisting guardians financially to ensure hospital visitations to access help for their child and address this stressor would seem beneficial.^[12]

Awareness of the child’s condition was generally poor. A lack of knowledge on managing symptoms associated with chronic disease and disabilities is an important factor known to lead to stress in a caregiving situation.^[8,13] In low-resource settings like Malawi, where basic medical care is limited and specialist services unavailable, education regarding the disease, managing symptoms, and prevention of possible complications is especially important. All guardians wanted health and hygiene education.

Involvement in such extensive care for loved ones unsurprisingly results in substantial physical and emotional

stress.^[10,11] Interestingly, overall emotional or psychological challenges were not reported as a priority challenge but only indirectly suggested to be an issue when asked what benefit would be gained from meeting other mothers in a similar situation. Increased social support has shown to positively correlate with the life satisfaction of caregivers with children with disability.^[14,15]

A better understanding of caregiving challenges and the unmet needs of guardians can inform the design of targeted interventions aimed at supporting, educating and empowering them: a gap that currently remains unfilled.

RECOMMENDATIONS

We would recommend using the results from this situation analysis to advocate and plan for services for guardians of children with disabilities and/or chronic illness in terms of:

- Educating guardians regarding the condition of their child, including the prognosis and possible complications of the disease
- Providing guardians with financial support for transportation and consultation costs to improve health seeking behaviour
- Providing nutritional education and support, especially for the guardians of children with diabetes and CP
- Giving guardians education regarding hygiene

Additionally, since most of the children and guardians included in this study visit the NMH paediatric outpatient clinic on a regular basis, we would recommend:

- Developing a database of children that frequent the paediatric clinic, identifying the types and number of impairments.
- Gathering more information regarding the demographics of the guardians, including: age, marital status, number of children in the household, educational level and monthly income.
- Clustering guardians of children with specific conditions to come on a given day, which would allow targeted educational training regarding their disease and prognosis

- Informing and assisting guardians in applying for social welfare services available to them.
- Disability should be included in the curriculum for training of all health workers



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MT Bulletin of the Netherlands Society for Tropical Medicine and International Health
ISSN 0166-9303

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