

Social Sciences for Severe Stigmatizing Skin Diseases (5S Foundation), Ethiopia

Report of the Joint 5S Foundation and WASH-NTD and LF/Podo Technical Working Group Consultative Workshop



Picture 1: 5S Foundation Ethiopia and WASH-NTD and LF/Podo Technical Working Group Workshop Participants

December 22, 2021
AZZEMAN Hotel
Addis Ababa, Ethiopia

Brighton and Sussex Centre for Global Health Research



@GlobHealth_BSMS



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MINISTRY OF HEALTH-ETHIOPIA
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ACRONYMS

5S	Social Science for Severe Stigmatized Skin Diseases
AAU	Addis Ababa University
FMoH	Federal Ministry of Health
HIV/AIDS	Human Immuno Virus/ Acquired Immuno Deficiency Syndrome
ICS	Impact Communication and Engagement Strategy
IOCC	International Orthodox Christian Charities
LF	Lymphatic Filariasis
NaPAN	National Podoconiosis Action Network
NGO	Nongovernmental Organization
NTDs	Neglected Tropical Diseases
OSSSREA	Organization for Social Science Research in East and Southern Africa
SNV	Stitching Nederlandse Vrywilligers/ Netherlands Development Organization
UNICEF	United Nations Children's Fund
WASH	Water Sanitation and Hygiene

1 BACKGROUND

Social Science for Severe Stigmatised Skin Diseases(5S) Foundation is a four-year project funded by the UK's NIHR. The Brighton and Sussex Medical School (BSMS) as lead coordinator from the UK; the project is being implemented in three African countries--Ethiopia, Rwanda, and Sudan. The project focuses on three neglected tropical diseases: Podoconiosis, Scabies and Mycetoma. By adopting social science methods and perspectives, 5S project aims to contribute to the efforts underway to eradicate these NTDs and their socio-economic burdens. Also, strong south-north and south-south collaboration among the implementing institutions, skill transfer and building the capacity of emerging researchers are among the aims of the project.

The 5S project Ethiopia since its inception in January 2021 has built a strong relationship with its stakeholders. As part of the collaborative endeavours, the project held a consultative workshop with WASH-NTD and LF/Podo Technical Working Group Members on the 22nd of December 2021. This half-day workshop, which was held at AZEMAN Hotel, Addis Ababa, brought together about 26 (3 female) representatives from NGOs and the Federal Ministry of Health to identify the focus of their collaboration on WASH-Skin NTDs.

The workshop aimed to align the 5-S project objectives with the activities of the National WASH-NTD and LF-Podo Technical Working Groups. It was held with the hope that the workshop would foster better coordination and cooperation among the concerned stakeholders in fighting stigma against Podoconiosis and Scabies. Beyond this, it aimed at providing the opportunities to see the contribution of social sciences perspectives to the national Skin NTD program, the 3rd master plan and national NTD guidelines.

Garedew Yilma, the project coordinator of the 5S Ethiopia, welcomed participants and briefed them on the agenda of the workshop. He also invited the participants introduce themselves, the organisations they represented along with their roles. This was followed by an opening speech made by Professor Getnet Tadele, country representative of the 5S Ethiopia project. In his remark, Professor Getnet expressed his gratitude to the participants for attending the meeting.

The opening speech was then followed by four consecutive presentations by Professor Getnet Tadele and Ato Alemu Tesfaye from 5S Ethiopia project and Ato Anteneh Mekonnen and Ato Mosse Tamiru from the Federal Ministry of Health (FMoH). A short movie on podoconiosis, which was produced by 5S Ethiopia public engagement team, was played for the participants. Finally, the meeting ended with

discussions and Question and Answer session on the presentations and the context of collaboration between 5S and the stakeholders.

2 PRESENTATIONS

2.1 SOCIAL SCIENCES FOR SEVERE STIGMATISING SKIN DISEASES (5-S FOUNDATION): AN OVERVIEW OF THE 5-S FOUNDATION: PROFESSOR GETNET TADELE

The presentation highlighted that 5S project will attempt to overcome the conundrum of neglect at three levels. First, neglect of three tropical diseases: podoconiosis, mycetoma and scabies. Secondly, neglect of the affected patients and communities at different levels, and finally the neglect of the discipline of social science. Professor Getnet asserted that empirical research informed by robust theoretical perspectives in social sciences can help understand the underlying and complex issues related to NTDs and



Picture 1: Professor Getnet Tadele, PI and Country Representative of 5S Ethiopia project

to help design culturally viable interventions. He also highlighted the guiding framework and the proposed methodology of the project. He emphasized on the expected impacts of the project, which is to end the neglect of two conditions through embracing social science perspectives implicated at micro, meso and macro levels.

2.2. 5S ETHIOPIA PROJECT IMPACT COMMUNICATION AND ENGAGEMENT (ICE) STRATEGY AND COMMUNICATION ACTIVITIES: ALEMU TESFAYE

Alemu Tesfaye, a Public Engagement Officer of 5-S Foundation Ethiopia Project, and Knowledge and ICT Manager of Organization for Social Science Research in East and Southern Africa (OSSREA) highlighted major activities carried out in relation to communication, stakeholder engagement, and collaborations since the inception of the project. Another



Picture 2 Alemu Tesfaye, Public Engagement officer at 5S Foundation, Ethiopian Project

focus of Alemu's presentation was on the theory of change. He discussed three important levels of interventions where the project envisions change to take place. These include, macro (national/regional policy agenda), meso (community awareness and action against stigmatization), and micro (individual experience and wellbeing). He also talked about the aim to establish a Community of Practice, in order to involve the community during the intervention and help bring a sense of ownership and sustainability.

2.3. WASH-NTD TECHNICAL WORKING GROUP: OBJECTIVES AND RATIONALES: ANTENEHMEKONNEN

Ato Anteneh Mekonnen, social and behaviour change and WASH expert for NTDs at the Ministry of Health, presented the objectives and rationale of the WASH-NTD Technical Working Group. He clarified Ethiopia's identified priority NTDs, basic sanitation, and drinking water source, linkages between WASH and NTDs, evidence that shows the important role of WASH in NTD transmission, enabling guidelines and tools, and the importance of collaboration with 5S Foundation. The core activities of the WASH-NTD Technical Working Group, according to Ato Anteneh, include WASH toolkit (implemented at Wereda (district) level), Harmonized message, programme framework (only at national and regional levels) and WASH and NTD landscape analysis. His presentation reveals that more than 250 Weredas have received training on WASH toolkit. It was also highlighted that:



Picture 4: Anteneh Mekonnen, Social Behaviour Change and Wash Expert for NTDs at the FMoH

“The current basic sanitation coverage in Ethiopia ranges from 6% in Somalia region to 49% in Addis Ababa, the capital city, while the improved source of drinking water ranges from 47% to 99% in the same areas respectively.”

2.4. NATIONAL LF/PODO TECHNICAL WORKING GROUP: *ESTABLISHMENT, AIMS, MISSION, AND OPERATIONS*: MOSSE TAMIRU

According to Ato Mosse, the technical working group was established to effectively address the burden of these two diseases and reverse their adverse trends in Ethiopia. The group comprises of people from the ministry of health, AAU and NGOs working on Podo/LF. The working group has a range of activities including the:

- Completion of the nationwide LF/Podo mapping,
- Development of a series of national and regional

LF/Podo action plans,

- Critical review and providing technical guidance for a smooth progress towards elimination,
- Production and dissemination of evidence-based recommendations

The presentation indicated that the LF programme set a goal of eliminating lymphatic filariasis by 2020, while the podoconiosis programme aims to eliminate podo from Ethiopia in 2030.



Picture 5: Mosse Tamiru from F.MoH

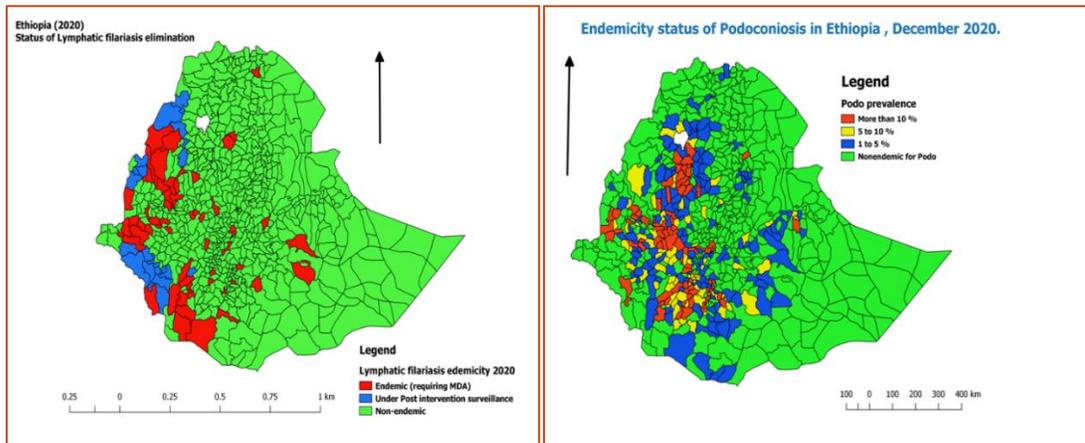


Figure 6: Endemicity Status of Lymphatic Filariasis (2010) and Podoconiosis (2020) in Ethiopia

3. SHORT MOVIE ON PODOCONIOSIS

A short educational movie titled “Barefoot,” which was produced by 5S Ethiopia public engagement team, was screened for the workshop participants. Barefoot

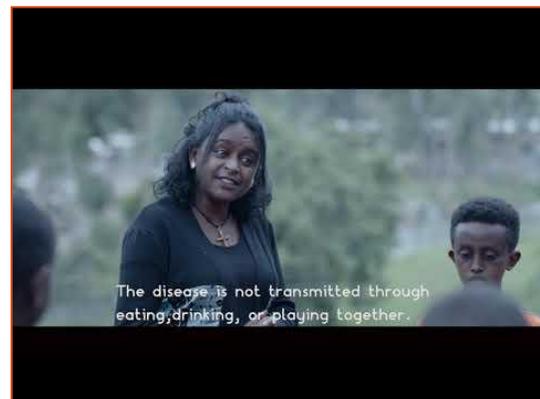


Figure 7: Barefoot: A short movie on podoconiosis

discusses a range of issues including an etiological belief and attempts to challenge discriminations and social stigma related to the disease.

4. QUESTIONS AND ANSWERS

Dr Teshome Gebre, Strategic Advisory Board members of 5S project, chaired the discussion session. He reiterated the messages of professor Getnet on the role of social science in NTDs by mentioning his experiences of working on NTDs. He mentioned a special situation where the involvement of a social science perspective helped a guinea worm project in South Omo address challenges that they could not manage to overcome through a biomedical perspective. The discussions were guided by the questions raised on the four presentations, on the movie, and on the 5S foundation.

Question #1: Dr Asrat Mengiste from CDT-Africa:

Dr Asrat asked questions related to the neglect of Mycetoma in Ethiopia and the need for integration of PhD projects. First, he explained that he had treated Mycetoma patients, who were in a serious condition and needed their legs amputated. He, therefore, believed that Mycetoma is highly neglected in Ethiopia and the 5S foundation should have included it in its project. Secondly, given that integration in research is becoming common these days, the 5S Ethiopian PhD projects should integrate both podo and scabies instead of working exclusively on each disease.

Responses:

Dr Teshome: the reason for the exclusion of mycetoma is attributed to the lack of a nationally representative survey on the disease. Once this has been done, it will probably be included in the upcoming NTD master plan.

Professor Getnet responded that if there is adequate evidence to believe Mycetoma is a public health burden in the country, it will be considered in the future. Regarding the issue of integration, 5S is a research project; it is not a big NGO. Although the project firmly believes in the importance of integration, integrating as many NTDs as possible is beyond the capacity of the project. He also mentioned that the project produce research findings and undertake small-scale intervention activities. Therefore, it should be seen from that angle.

Question # 2: Mebratu from NaPAN:

Ato Mebratu's question focused on the delays in the implementation of the MoU signed between NaPAN and 5S Ethiopian project on public engagement activities. He wondered why it took 5S a bit longer than expected to materialise their agreement.

Response:

Prof. Getnet responded that the collaboration with NaPAN was not originally part of the project design; it came lately while implementing the project. He concurred with Ato Mebratu on the fact that the implementation of the MoU took relatively longer than they anticipated, and believed the reason was due to a lengthy approval process from the donors' side.

Question #3: Gadisa from SNV:

Ato Gadisa remarked on the vital role of WASH in the prevention of NTDs. He also stated that access to WASH has unfortunately been hampered by two factors: non-functionality and donor's lack of interest to construct new schemes:

“WASH is so vital for NTD prevention. The question is, where is the water? Donors do not want to construct new water schemes. And non-functionality is the biggest problem in the country. So, we wanted to reduce that. So far, we maintained more than 320 water schemes.”

In light of these challenges, he suggested 5S to engage in the maintenance of non-functional water projects. He finally asked how 5S could be related to WASH-NTD and the reason for a lack of proper structure and coordination on WASH-NTD from zonal to Wereda levels.

Response:

According to Professor Getnet, maintaining or restoring non-functional water projects is an effective strategy. However, he disclosed that 5S cannot engage in such activities because of its focus on research and limited scope. Professor Getnet further explained that the outcomes of the project are the impacts of research findings on the community in relation to communications and interventions in stigma and neglect, and not as such large-scale interventions and investment in infrastructure.

Question # 4: Solomon Gadisa:

According to Solomon, social science perspectives have been set aside from NTD interventions. He believed that 5S should be appreciated for trying to bridge this gap. He also noted that the coming of the 5S project coincides with the time when the new NTD strategy has given attention to social aspects. Following this, he forwarded two questions. The first one is about the scope of the 5S project in dealing with NTDs while the existing projects are nearing completion. His second question was about the video. He doubted if the video showed the effect of red clay soil on exposure to podoconiosis. He also questioned the movie for using a young boy as a patient of podoconiosis, when in fact it should be an adult because podo is believed to progress with prolonged exposure to the soil.

Response:

In response to Solomon's questions, Prof. Getnet made clear that 5S is a four-year research project, of which two years have already gone. He also explained that the coverage of the project is limited by its life span. Intervention activities are also restricted to areas where the research is conducted and the relationships the project establishes with various stakeholders.

Regarding the question about the short film on podo, professor Getnet explained that the movie was recorded around Addis Ababa during the rainy season and they didn't go to the area with red clay soil. The reason why one could see mud in the video instead of red soil was because the movie was shot in Addis. The main aim of the film, according to Professor Getnet, was to inform the audience about the stigma and discrimination because of walking barefoot.

Professor said the project team often struggles to find Amharic name for podoconiosis while preparing the communication materials. Thus, he asked if the participants—the technical working group—can suggest an appropriate Amharic term for the disease.

Response:

According to Musse, the Ministry of Health use the term “telalafi yalhone yezihone beshita” or non-communicable LF or podo. This disease, according to Tsige from IOCC, has different Amharic names including the one being used by the ministry. Other names she mentioned are *abataegir* and *gindegir*. She believed that all these Amharic names associated with podo are laden with discriminatory connotations. What has been suggested by Dr Teshome was to contact the Ethiopian Language Studies at Addis Ababa University or the Ethiopian Academy of Sciences for such naming.

Question #5: Belete:

He believed that since Podo has been addressed in the national NTD guideline, the findings of the 5S project can be used as inputs for the national policy and intervention endeavours. Belete's question was about the communication tools and materials. He specifically wondered if the communication tools are appropriate to the context of the community and if the community has been consulted and their social values have been considered during the preparation of the public engagement communication tools.

Response:

In his brief answer to Belete's question, Dr. Teshome said that the communication products will be developed within the framework of a community of practice where the communities can contribute their say in such issues.

Question #6: Mosse:

Ato Mosse started his question by suggesting 5S to consult MoH while preparing the communication materials. He thinks experienced members of the public relations team can help produce sound community outreach materials. He asked the following two questions:

- *Does 5S have preliminary findings that can serve as an input for the WASH-NTD and LF/Podo technical working group members?*
- *Why there is no logo of Addis Ababa University in the 5S communication materials?*

Ato Mosse's final thought was the need for the 5S project to work closely with other universities located within the geographical areas of the project. Such collaboration according to him can help a lot to effectively implement the national NTD program.

Response:

Professor Getnet said that the agreement was made not with Addis Ababa University, but it was with the Organisation for Social Science Research in East and Southern Africa (OSSREA). Addis Ababa University's lack of efficiency in running funds that come through the projects has been the major reason for 5S to look for alternatives. OSSREA has very smooth procedures to run financial activities.

5. WRAP UP DISCUSSION

The concluding discussion was chaired by AtoFikre Seife, National NTD Program Team Leader. AtoFikre said that strengthening collaboration and transferring it into the National program is highly

required. He also indicated that many NTDs have been emphasised in the 2022-2025 NTD program and there are ongoing medical interventions to the diseases. In addition to the medical aspects, attention must be paid to psycho-social rehabilitations of the patients. Finally, he disclosed that the third NTD master plan has five strategic pillars including community engagement, integrated skin NTDs, behavioural change, communications, and behavioural change material development. He stated that since these strategic pillars require the development of guidelines, the collaboration with the 5S project will have a significant role in making this happen.

Further Questions and Suggestions:

Ato Gadisa called for collaboration between the 5S project and local universities. He also hinted that WASH and NTD focused projects have budgets for the research. However, the budget is not used properly as it is being wasted on research done by inefficient and unprofessional consultants. The situation, according to Ato Gadisa, has created an additional burden for the projects because they are forced to do the research that consultants failed to properly conduct. He thinks that the solution is to make a platform where projects collaborate with academics and universities like the 5S projects, where PhD and master's students could also get funding for their projects.

Response:

Professor Getnet stated that through collaboration, quality research can be produced by PhD and masters' students with a very efficient budget. He assured that he and colleagues can recruit the students, as they usually do for their projects, and supervise them. He also pledged that his team is ready to collaborate whenever there is a need for social science professionals. In addition, the Ethiopian Society of Sociologists, Social Workers and Anthropologist (ESSSWA), which he is presiding currently, can be a good collaborator as it has chapters in many parts of the country.

Dr. Kibur explained where the 5S role could lay in relation to NTDs. He stated that the focus of 5S project is on stigma and discrimination associated with skin NTDs, like Podo and Scabies. First, 5S can use theoretical approaches to understand the issue, the meanings associated with the causes of the disease, to explore the most affected segments of the population, to suggest ways through which the spread of the disease could be prevented, to study the local contexts associated with the diseases, and come up with appropriate intervention strategies. Secondly, Dr Kibur continued, 5S helps decide how to bring behavioural changes and how the behaviours are structured in the social system. The 5S project can also apply social science perspectives to study health issues by using various methodological approaches like phenomenological and ethnographic approaches. Finally, he indicated that the 5S research team can also deliver training in connection with NTDS from the social science perspective.

Dr. Asrat told participants to view the areas of collaboration in the simplest way. He specifically suggested 5S to evaluate ongoing NTD related interventions in the country, including that of the WASH-NTDs and LF/Podo technical working group. He also believed that the 5S project can research by using all the Ministry of Health's structures from the federal to woreda levels. This collaboration, according to Dr Asrat, will pave the way for future big NTD projects.

Ato Mosse asked a question related to the sustainability of the project. He asked who his organisation will collaborate with once the 5S project phases out and any plans to make 5S project sustainable at the national NTD programs.

Response:

According to Dr Teshome, the project needs to be institutionalised and the MoU needs to be signed between the collaborating parties.

Finally, Haymanot from UNICEF suggested that the findings of the 5S research projects need to be shared under a central umbrella where everyone can easily access it.



Figure 8 Participants of the Discussion

6. THE WAY FORWARD

Ato Fikre once again called for attention to psycho-social supports and rehabilitation activities to avoid the stigma associated with podo and other NTDs like it is for HIV/AIDS. He also promised that the national NTD program at the ministry will keep supporting the activities of the 5S project and the 5S project needs to plan on how to engage in other NTD activities.

Professor Getnet also believed that the workshop created opportunities to get to know each other and laid a good foundation for future collaboration. Finally, he requested participants to open their doors for 5S researchers who will come to them for data collection.

7. ANNEX

Agenda

Time	Agenda	Facilitator/Presenter
8:30 - 8:45	Registration	5-S Team
8:45 - 9:00	Welcoming Speech	Prof. Getnet Tadele
9:00 - 9:30	An overview of the 5S Ethiopia project	Prof. Getnet Tadele
9:30 - 9:50	5S Eth project Impact Communication and Engagement (ICE) Strategy and communication activities	Alemu Tesfaye
9:50 - 10:10	Presentation on WASH-NTD Technical Working Group establishment, aims, mission and operations	AntenehMekonnen
10:10 - 10:30	Presentation on LF-Podo- Technical Working establishment, aims, mission and operations	MossieTamiru
10:30 - 10:45	Coffee Break	Azzeman Hotel
10:45 - 10:55	Short educational movie titled “ <u>Barefoot</u> ,”	5-S Team
10:55 - 11:45	Discussion on the presentations	Dr. Teshome Gebre
11:45 - 12:30	General Discussion on the following points: <ul style="list-style-type: none"> • How the 5S Eth project can closely collaborate with the WASH-NTD Technical Working Group and the National NTD Taskforce? • How social sciences perspectives contribute to the national Skin NTD program, the 3rd master plan and NTD national guidelines? • How to bring behavior changes in relation to Skin NTDs? • Communication and Message framing to fight neglect, stigma and discrimination towards NTDs • Other discussion points... 	Mr. Fikre Seife
12:30	Closing remark and way forward	Prof. Getnet Tadele
12:30 - 13:30	Lunch	Azzeman Hotel

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Social Sciences for Severe Stigmatizing Skin

List of Participants

S.N	Full Name	Sex	Organization
1	Dr. AsratMengiste	M	CDT-Africa
2	Dr. Teshome Gebre	M	Task Force for Global Health
3	KaldanMekete	F	End Fund
4	TsgeAmberber	F	IOCC
5	Lulu Mussa	M	Orbis
6	Mehammed Hassen	M	TCC
7	Kassa Bulcha	M	TCC
8	Belete Mengistu	M	RTI
9	Mebratu Mitiku	M	NaPAN
10	Sileshi Hailemeskel	M	Sight Savers
11	Gadissa Hailu	M	SNV
12	Desalegn Amanuel	M	GTM
13	Solomon Gadisa	M	LFTW
14	Yisfalem Ayelem	M	LFTW
15	Fikre Seife	M	MOH/NTD
16	MossieTamiru	M	MOH/NTD
17	AntenehMekonen	M	MOH/WASH-NTD
18	Haimanot Assefa	M	UNICEF/C4D
19	Dr. Beshah Mogesse	M	UNICEF/C4D
20	Prof.Getnet Tadele	M	5-S Eth
21	Dr. KiburEngidawork	M	5-S Eth
22	Alemu Tesyaye	M	5-S Eth
23	TseganeshMulugeta	F	5-S Eth
24	Addisu Tsgegaye	M	5-S Eth
25	GaredewYilma	M	5-S Eth
26	Alazar Emiru	M	5-S Eth