



Report of the Inception Workshop of the Social Sciences for Severe Stigmatizing Skin Diseases (The 5S Foundation) Project Ethiopia



Figure: 5S Foundation Project Ethiopia Inception Workshop Participants

28 January 2021

Ras Amba Hotel, Addis Ababa

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Abbreviation and Acronyms

AARA	Administration for Refugee and Returnee Affairs
AAU	Addis Ababa University
BSMS	Brighton and Sussex Medical School
CC	Community Conversation
FMoH	Federal Ministry of Health
NaPAN	National Podoconiosis Action Network
NGO	Non-Governmental Organizations
NTD	Neglected Tropical Diseases
OSSREA	Organization for Social Science Research in Eastern and Southern Africa
PI	Principal Investigator
PHCU	Primary Health Care Unit
SBCC	Social and Behavior Change Communication
TWG	Thematic Working Group

1 Background

The 5S foundation project aims to end neglect of two stigmatizing skin diseases (Podoconiosis and Scabies) in Ethiopia through bringing the social sciences to bear on these conditions by identifying interventions informed by social science perspectives at the level of the patient, the community and national and international policy. Podoconiosis is a progressive, debilitating form of leg swelling experienced by barefoot farmers, and scabies an extremely itchy infectious condition caused by skin burrowing mites. These conditions are huge public health problems and attract stigma towards patients in Ethiopia. The conditions mainly afflict the poor and have not been given sufficient attention. Social sciences are in best position to understand the effect of poverty and other structural factors on the disease. Yet, little effort is made to utilize the perspective of social sciences to this end.

Cognizant of this, the project aims to utilize social sciences' theoretical frameworks and research methods to end the neglect of podoconiosis and scabies and the stigmata associated with the conditions. Part of this initiative is building the capacity for social science disciplines in Ethiopia. Accordingly, the project runs a postdoctoral study and a number of PhD research projects on scabies and podoconiosis.

The 5S foundation has a strong commitment to engage the public in the project activities. A public engagement team has been set up to disseminate information about the project and receive feedback from stakeholders including the local community. As a first step to involve the public, the team organized a one-day inception workshop on January 28, 2021 at Ras Amba Hotel, Addis Ababa-the capital of Ethiopia bringing together various stakeholders from different parts of the country. The workshop agenda is included in Annex 1. This report summarizes the results of the workshop.

The workshop aimed to get buy in and align the 5-S project objectives with the stakeholders' activities. 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 gathering inputs from the participants for the realization of project objectives.

A total of 39 participants (nine female) from federal and regional government organizations, academia, Non-Governmental Organizations (NGOs), Health Institutions and professional association attended the workshop. A list of participants is included in Annex 2. The workshop was kicked off by Professor Genet Tadele, country PI of the project, by welcoming and expressing his sincere gratitude to the attendees. Professor Getnet gave a brief history of the project and introduced the team members before inviting the welcoming and opening speakers. The welcoming speaker, Dr. Truphena E. Mukuna Executive Director of Organization for Social Science Research in Eastern and Southern Africa (OSSREA), highlighted the core objective of OSSREA and underscored the need for this kind of dialogue with people from academia and government agencies, and from civil society organization to create linkage and synergy. The opening speaker, Dr. Mitike Molla V/President for Research & Technology Transfer, Addis Ababa University and Strategic Advisory Board (AAU) member of 5-S Foundation, also underlined that the social sciences have been underutilized in relation to NTDs. In addition, opportunities to explore the social contexts of these conditions and the policies designed to control them in light of social data have mostly been missed. As a result, designing and implementing a research project which focuses on the social science perspective is very important to fill these gaps.

After the welcoming and opening speeches, various papers related to the project and community theatre on podoconiosis and scabies were presented to the invited participants. The participants actively engaged in each presentation by raising questions and providing constructive comments that would contribute to the successful accomplishment of the project objectives.

Summary of Presentations and Discussion Sessions

In this section, a summary of presented papers about the project, research proposals of post-doctoral research fellow and PhD students, and community theatre on podoconiosis and scabies is provided. In each sub sections, the focus of each presentation is summarized and followed by respective discussions.

1.1 Social Sciences for Severe Stigmatizing Skin Diseases (5-S Foundation): An over view of the 5-S foundation project

Professor Getnet Tadele, Country Principal Investigator (PI) of 5S project, provided an over view of the 5-S foundation .Professor Getnet presented the vision, aims and expected impact of the project. He also highlighted how social science perspective can contribute to achieve the project’s vision and aims. The guiding framework of the parent project was also presented. In addition, Professor Getnet discussed the proposed methodology for the project. .



Figure 0.1: Professor Getnet Tadele, Country PI of 5-S project while giving his presentation

1.2 Post-Doctoral and PhD Research Proposals

This subsection provides summaries of presentations of the Post-Doctoral research fellow and PhD students’ research proposals and the corresponding discussions.

1.2.1 Evaluation of an existing social intervention which aims to mitigate NTD-related stigma in Ethiopia (5-S-foundation)

Dr. Kibur Engdawork, a post-doctoral research fellow in the 5-S research project, presented his research proposal titled *Evaluation of an existing social intervention which aims to mitigate*

NTD-related stigma in Ethiopia. His presentation included a background information, study aims, study design and setting, anticipated outputs and progress to date. . He explained that a social intervention known as “Next Steps for Podoconiosis Patients in Amhara Region” has been selected for the assessment and will be evaluated using The context and implementation of complex intervention (CICI) framework.



Figure 0.2: Dr. Kibur Engdawork, post-doctoral research fellow at 5S project

Discussion: Responding to a request to elaborate on the selection criteria used to choose an intervention for the evaluation, Dr. Kibur explained that a predefined set of criteria, grouped into relevance and exclusion, has been used to select one intervention from 11 social interventions that have been implemented to prevent and control podoconiosis. Interventions that have stigma reduction programs were deemed to be relevant for the evaluation; and those interventions that won't be active during the fieldwork were excluded from the selection. He also stated that some interventions were precluded from the selection as their sites may not be accessible to researchers due to security concerns.

1.2.2 Understanding how precarity & marginalization affect refugees' vulnerability to, illness experiences of & responses to scabies in Ethiopia

Addisu Tsegaye, a doctoral student at 5-S research project, presented his proposed research titled *Understanding how precarity & marginalization affect refugees' vulnerability to, illness experiences of & responses to scabies in Ethiopia.* Mr. Addisu presented about the context of

scabies in Africa in general and Ethiopia in particular. He also presented the objectives and research design of his proposed study. Furthermore, he explained that Structural Violence will be used as an analytical framework in his research project.



Figure 0.3: Addisu Tsegaye, doctoral student in the 5-S project

Discussion: Key discussions on Addisu’s presentation were:

- The feasibility of conducting ethnographic research given strict legal context of refugee camp administration and the difficulty of accessing informants. Mr. Addisu explained that he had made discussions with the federal and regional Administration for Refugees and Returnees Affair (ARRA), who expect the researcher to provide letter from the Brighton and Sussex Medical School (BSMS) and prepare ToR in advance.
- The second issue of discussion was how he is going to deal with people who are ill with scabies that he may encounter during the fieldwork? Professor Getnet, Country PI, suggested that the researcher will arrange referral linkages for people suspected of the disease.

1.2.3 Everyday life of people affected by scabies in Amhara regional state, Ethiopia

Dereje Wonde, a doctoral student in the 5S research project, presented his research proposal titled *Everyday Life of People Affected by Scabies in Amhara Regional State, Ethiopia*. Mr.

Dereje gave background information of his proposed study, existing gaps, objectives, and research design (including method of data collection and data sources). He also briefly explained his proposed research guiding frame work- Theory of Social Suffering and Structural Violence.



Figure 0.4: Dereje Wonde, doctoral student in the 5-S project

Discussion: The following issues were raised after his presentation.

- The relevance of including other theoretical frameworks such as Arthur Kleinman's Explanatory model of illness behavior parallel to his social suffering theory. Mr. Dereje stated that he would consider using the model to observe the health seeking behavior of individuals affected by scabies).
- Mr. Dereje was asked to reflect on why the period 2015 was associated with scabies outbreak in the Amhara region in particular and Ethiopia in general. Dereje replied that although scabies is an ancient health disorder in Ethiopia that has been affecting people for a long period of time, the severe water shortage and drought following the incident of El Nino was regarded as the immediate cause for the widespread outbreak of scabies in the Amhara region in 2015.

- He was also asked how infrastructural and institutional determinants of scabies prevalence will be approached by his study. Dereje explained that his study embraces both micro level realities of scabies and meso level factors contributing to the prevalence of scabies in the study community.

1.2.4 Communication for Understanding: Role of Community Conversations to Empower Community and Reduce Stigma against Podoconiosis Patients in Amhara Region, Ethiopia

Tseganesh Mulugeta, a doctoral student at Addis Ababa University and a public engagement officer of the 5S foundation presented her research proposal titled *Communication for Understanding: Role of Community Conversations to Empower and Reduce Stigma against Podoconiosis Patients in Amhara Region, Ethiopia*. In her presentation, Tseganesh provided a brief background, problem statement, objectives, study design and conceptual framework of her proposed project.



Figure 0.5: Tseganesh Mulugeta, doctoral student in the 5-S project

Discussion: The following were points of discussion:

- One of the participants stated that the focus on health communication is significant and remarkable. Behavior change communication is the most widely used approach but difficult to implement. The participant asked how Tseganesh is going to measure behavioral changes. She responded to the question by underlining that her research will focus on the role of communication (community conversation) to create awareness and

empower the community to enhance shoe-wearing behaviors and reduce stigmatizing attitudes against podoconiosis patients.

- Another participant also stated that there is always a relapse of old behavior after the implementation of intervention to change behavior. There are also different superstitious attitudes and perceptions regarding podoconiosis that hinder the intervention. Tseganesh was asked how she is going to achieve her objectives in this regard. She replied that her focus is not whether community conversation brings behavior change or not. Rather, her intention is to create understanding and empower the community (by using community leaders) to make their own decision/ choice to wear shoes (shoes wearing behaviors) and reduce stigmatizing attitudes against podoconiosis patients. She underlined that in her study, communication will be used not as a means but an empowerment process.
- Tseganesh was asked whether she has baseline studies for her research in implementing her intended research design. Similarly, she was also asked how she is going to control the effect of confounding variables in the quasi-experimental research method. She said that there are so many baseline studies that she used to support her arguments including Dr. Kibur's PhD dissertation. She also added that different procedures will be used to control the effect of confounding factors in her quasi-experimental research.
- A participant also asked what is unique about her study given that community conversation has been implemented by so many NGOs and governmental organizations as an intervention. She stated that she is not going to optimize previous CC interventions. However, she stated that she might use these interventions as a baseline for her research. As a researcher, her intervention will introduce an approach which includes different empowerment communication activities such as a training, community theatre, first-hand experience of podoconiosis patients and using communication materials such as posters.

1.3 5-S Foundation Ethiopia Project: Impact, Communication and Engagement (ICE) Strategy

Alemu Tesfaye, Public Engagement Officer of 5-S Foundation Ethiopia Project and Knowledge and ICT Manager of (OSSREA), made a presentation on the 5-S Project's impact, communication and engagement strategy to the participants. In his presentation, Mr. Alemu gave a due emphasis that the project envisions change at three levels: macro (national/regional policy agenda), meso (community awareness and action against stigmatization), and micro (individual

experience and wellbeing). He also briefed the participants about the target audiences, communication channels, activities and outputs of the project.



Figure 0.6: Alemu Tesfaye, Public Engagement Officer 5-S Foundation Ethiopia Project Knowledge and ICT Manager

Discussion: there was no question or comment given to Mr. Alemu’s presentation during the discussion session. But during the lunch break one of the participants advised to include shoe producers in the *stakeholders list* specially the ones who are already producing for podo patients.

1.4 Forum Theater on Podoconiosis and Scabies

Following the presentation of all papers, a community theater, focused on podoconiosis and scabies, was delivered to the audience. All of the participants were highly immersed in the theatre. The theatrical performance showed misconceptions about podoconiosis and scabies; how this could affect patients’ health and access to treatment.



Figure 0.7: AAU Theatrical Art Students while presenting theatre on podoconiosis and scabies

Discussion: appreciating the strong sides of the theatre, the participants also provided some constructive comments to the producers of the theatre. For example, there is a scene where one of the performer attributes podoconiosis to the sin (stealing oxen) committed by his grandparent. ‘The actor’ believed that podoconiosis is not treatable by modern medicine. On the other hand, one of the relatives to the family was struggling to convince the patients to visit health institutions for treatment. In this regard, it will be better if there is scene that shows a person who has committed sin/crime but not affected by podoconiosis or scabies. This will easily influence the community to detach the association between sin/crime and podoconiosis or scabies.

Breakout session and General Discussion

In addition to discussion after each paper and theatrical presentations, breakout session was held. Three groups were formed. The groups were arranged in such a way that each group comprises

participants from different background such as academia, health, NGO, civil society organization, and media.



Figure 0.1: Discussion Groups

The summary of discussions made in the groups is presented in the following sub sections.

1.5 Alignment of 5-S project with participants' activities, plans and the country's policies

Each discussion groups were asked whether the project is in line with their activities, plans and the country's policies. All the discussants, who came from different background, replied that the project aligns good fit with their activities. They noted that the project fits well with academic activities in terms of teaching, research, and community services. For instance, it converges with courses such as medical sociology, medical anthropology, rural and development sociology. It can be further researched by the university staff members, students, and other organizations. The

research result from the study can be an input for policy formulation. It is also reflected that the 5-S foundation aligns with the country's NTD master plan as it deals with two of the nine NTD priorities in Ethiopia. In addition, it aligns with the NaPAN's plan of developing SBCC strategy for eliminating podoconiosis.

One of the three discussion groups suggested that research on podoconiosis and scabies needs to focus on intervention (implementation research). It is also underlined that the research project should come with comprehensive data since it might be used as an input for policy formulation.

1.6 Reflection on problems/challenges with existing policies and guidelines

Most of the participants broadly endorsed that the existing policy about podoconiosis and scabies is at an interim level. There is lack of access to the existing policies and guidelines at all levels from region to Primary Health Care Unit (PHCU). In addition, the existing policies and guidelines were not informed by the social science perspective to sustainably control and eliminate the NTDs. The existing guidelines only focus on public health perspective but no or little attention to social science perspectives.

1.7 Proposed approaches to improve/refine NTD policy, guidelines and strategies

Discussants in each group were asked to suggest an approach in order to improve/refine NTD policy, guidelines and strategies and to make them informed by the social science perspectives. The following suggestions were made by the different groups.

- ☛ The existing policies, guidelines, and strategies lack social aspects, and social scientists' perspectives. Therefore, social scientists should be involved in the formulation and implementation of policy
- ☛ Organizing social science conferences and symposiums on the NTDs. This will play a huge role in informing NTD policy, guidelines and strategies from social science perspectives.
- ☛ Parallel to organizing social science conference and symposium on NTDs, creating a forum that brings public health experts and social scientists on board will prove to be effective
- ☛ It was stated that the active engagement of social scientists in the NTD Task force and Technical Working Group (TWG) is vital.

- ☛ It was also suggested that the policy needs to be participatory and follow a bottom-up approach in a bid to make it inclusive and comprehensive.

1.8 Recommendation to improve stakeholder engagement and policy debate by various NTD actors and social scientists

Each discussion groups provided suggestion on how to improve stakeholder engagement and policy debate by various NTD actors and social scientists on issues related to skin diseases and associated stigma. Accordingly, it was suggested that all concerned stakeholders such as community leaders, religious leaders, and opinion leaders should be invited and engaged in training and workshop on how to end podocniosis and scabies.

More specifically, organizing regular stakeholder meeting and workshops, establishing strong networking that link NTD actors and social scientists, and public and community mobilization through electronic and print media were recommended

1.9 Recommended channels in the conversation of NTDs and their social dimensions

Participants in each discussion groups were also asked to suggest communication channels which best suit in order to increase the number and type of actors involved in the conversation of NTDs and their social dimensions. The following channels were recommended

- ↻ Preparing research symposium on NTDs and skin diseases and associated stigma
- ↻ Using community radio/mass media and undertaking social media campaign
- ↻ Identifying and engaging appropriate stakeholders from various backgrounds
- ↻ Using health extension workers, health development army, and psycho-social workers to communicate interventions about skin diseases and associated stigma
- ↻ Establishing information desk at Kebele level and using existing administration structures in order to disseminate information or campaign for treatment or awareness
- ↻ Using religious institutions: For example, awareness raising about NTDs will be successful if it is made on Sundays around churches (for Christians) and Fridays around Mosques (for Muslims) by using religious leaders.

1.10 What could participants contribute to the success of the project

Finally, the discussants in each group were asked what and how they would like to contribute to the success of the project. The discussants expressed their willingness to contribute to the

success of the project in accordance with the mandate of the institutions and organization they belong to as follows.

- Participants from academic institutions mentioned that their contribution will be by planning and executing NTDs and skin diseases and associated stigma in research and community services.
- Participants from FMOH said that their contribution will be through the provision of innovative BCC strategies and by creating the enabling environment and sharing information.
- Participants from ARRA also stated that their organization will contribute by providing the required permit and support for the research in refugee and returnee settings.
- Similarly, NaPAN representative promised that they will support and engage in patient identification and community mobilization
- Most of the participants in each groups also underlined that they will contribute to the success of the project by disseminating information about the treatment of podocniosis and scabies through social networks and creating awareness about the problem by using the existing structures

Closing Remarks

Professor Getnet thanked all the participants for their active and enthusiastic engagement and providing constructive comments and suggestions, and willingness to contribute for the success of the project.

Professor Getnet also underlined that the suggested inputs and comments will be addressed. In addition, he reaffirmed that stakeholders who were not invited for this inception workshop will be invited in future workshops. He asked the participants to link 5S team with other stakeholders in order to engage them in future workshops and other public engagement activities. He also thanked the project coordinators based at BSMS and National Institute for Health Research (NIHR).

Finally, the business of the day was concluded by giving applaud to all members of the project team for their unreserved commitment and contribution to the success of the workshop.

Annex

Annex I: Workshop Agenda

Time	Agenda	Presenter	Facilitator
8:30 – 8:50	Registration	5S Team	5S Team
8:50 -9:00	Introduction	Prof. Getnet T.	
9:00 - 9:10	Welcoming speech	Dr. Truphena E. Executive Director OSSREA	
9:10 - 9:20	Opening Speech	Dr. Mitike M. V/President for Research & Technology Transfer, AAU and SAB member of 5S F.	
9:20 - 9:50	An over view of the 5-S foundation project	Prof. Getnet T. Country PI of 5S project	Dr. Teshome G.
9:50 – 10:10	Evaluation of an existing social intervention which aims to mitigate NTD-related stigma in Ethiopia.	Dr. Kibur E.	Dr. Teshome G.
10:10 - 10:30	Understanding how precarity & marginalization affect refugees' vulnerability to, illness experiences of & responses to scabies in Ethiopia	Addisu T.	Dr. Teshome G.
10:30 – 10:55	Discussion		Dr. Teshome G.
10: 55 – 11:10	Coffee Break		Ras Amba Hotel
11:10 – 11:30	Everyday life of people affected by scabies in Amhara regional state	Dereje W.	Temesgen C.
11:30 - 11:50	Communication for Understanding: Role of Community Conversations to Empower and Reduce Stigma against Podoconiosis Patients in Amhara Region, Ethiopia	Tseganesh M.	Temesgen C.
11:50– 12:05	Impact, Communications and Engagement (ICE) Strategy- Ethiopia	Alemu T.	Temesgen C.
12:05 – 12:30	Discussion		Temesgen C.
12:30 – 13:30	Lunch Break		Ras Amba Hotel
13-30 - 14:00	Community Theater on Podoconiosis	Actors	Zerihun B.
14:00 - 14:45	Breakout session / Group discussion	Participants	Prof. Getnet and Dr. Kibur
14:45 - 15:30	General Discussion		
15:30	Closing remark		Prof. Getnet T.
Tea and Coffee			

Annex II: Names and Organizations of Inception Workshop Participants

S.N	Name	Sex	Organization	Responsibility	Region
1.	Dr. Truphena E. Mukuma	F	OSSREA	Executive Director	Addis Ababa
2.	Dr. Mitike Molla	F	Addis Ababa University	V/President for Research & Technology Transfer & SAB member of 5S Foundation	Addis Ababa
3.	Prof. Getnet Tadele	M	AAU, 5S Project Ethiopia	Country PI	Addis Ababa
4.	Dr. Ruth Likassa	F	ALERT	Consultant	Addis Ababa
5.	Dr. Teshome Gebre	M	Task Force for Global Health	Region Director	Addis Ababa
6.	Dr. Saba Lambert	F	ALERT	Clinical Research Fellow	Addis Ababa
7.	Fikre Hailekiros		Network National Podoconiosis Action Network	Executive Director	Addis Ababa
8.	Fikire Siefe	M	Ministry of Health	Ethiopia National NTD Task Force Team Leader	Addis Ababa
9.	Anteneh Mekonen	M	Ministry of Health	WASH-NTD Technical Working Group Expert	Addis Ababa
10.	Heven Sime	F	Ethiopian Public Health Institute	Researcher	Addis Ababa
11.	Melisew Chanyalew	M	Amhara Bureau of Health	Director of Disease Prevention and Control dept.	Amhara
12.	Addisu Abebe	M	Amhara Bureau of Health	NTD Case Team leader	Amhara
13.	Abrham Amsalu	M	Amhara Public Health Institute	DHEM Director	Amhara
14.	Tilahun Muche	M	Amhara Bureau of Labor and Social Affair	Expert	Amhara
15.	Ojulu Ojulu Okello	M	Gambella Bureau of Labor and Social Affair	Bureau Head	Gambella
16.	Ojulu Omud	M	Gambella Bureau of Health	Maternal & Child Care Director	Gambella
17.	Daba Lamessa	M	Gambella Administration for Refugees and Returnees Affair	Head	Gambella
18.	Habtam Fikadu	M	Jimma University	Head, Department of Sociology	Oromia
19.	Hayelom Abadi	M	Wollo University	Head, Department of Sociology	Amahra
20.	Dr. Kibur Engidawork	M	AAU, 5S Project Ethiopia	Post Doc research Fellow	Addis Ababa
21.	Temesgen Chibsa	M	Addis Ababa	Lecturer and researcher	Addis Ababa

			University		
22.	Asabneh Molla	M	Addis Ababa University	Lecturer and researcher	Addis Ababa
23.	Tsige Amberbir	F	International Orthodox Christian Charities	Program Manager	Addis Ababa
24.	Eyob Welde Gebreal	M	Federal Administration for Refugees and Returnees Affair	Expert	Addis Ababa
25.	Frehiwot Nadew	F	CDT-Africa	S.C. Manager	Addis Ababa
26.	Desta Ayode	M	DAC Consultancy	Head and Researcher	Addis Ababa
27.	Zelalem Mekuria	M	Ministry of Social Affairs	Expert	Addis Ababa
28.	Hiwot Abbay	F	Ethiopian Society of Sociologist, Social Workers & Anthropologists	Program Coordinator	Addis Ababa
29.	Mengisteab Teshome	M	Ethiopian Press Agency	Editor	Addis Ababa
30.	Bikilla Ayelle	M	Addis Ababa University	PhD student	Addis Ababa
31.	Molla Yissmaw	M	Addis Ababa University	PhD student	Addis Ababa
32.	Mekuarua Asaye	M	Addis Ababa University	MA student	Addis Ababa
33.	Addisu Tsegaye	M	Wollo Univ. & 5S Project Ethiopia	PhD student	Addis Ababa
34.	Dereje Wonde	M	Jimma Univ. & 5S Project Ethiopia	PhD student	Addis Ababa
35.	Tseganesh Mulugeta	F	Bahirdar Univ. & 5S Project Ethiopia	PhD student	Addis Ababa
36.	Alemu Tesfaye	M	5S Project Ethiopia	Public Engagement Officer	Addis Ababa
37.	Zerihun Berhanu	M	5S Project Ethiopia	Community Theatre Specialist	Addis Ababa
38.	Alazar Emiru	M	5S Project Ethiopia	Finance Officer	Addis Ababa
39.	Garedew Yilma	M	5S Project Ethiopia	Project Coordinator	Addis Ababa
40.	5 actors (3 female & 2 male)		AAU	Actors	Addis Ababa
41.	Seven Kana TV crew members		Kana TV	Journalist, cameraman, director, light and sound man	Addis Ababa