

ASCEND LEARNING BRIEF

Strengthening Communication and Integration with WASH to Eliminate NTDs

Lessons from South Sudan

Ascend is managed geographically in two lots. Lot 1 focuses on 11 countries in East and Southern Africa and South Asia: Bangladesh, Ethiopia, Kenya, Malawi, Mozambique, Nepal, Sudan, South Sudan, Tanzania, Uganda, Zambia. We gratefully acknowledge the financial support provided by the UK Foreign Commonwealth and Development Office (FCDO) to fund the Ascend programme.

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Abbreviations

ASCEND	Accelerating the Sustainable Control and Elimination of Neglected Tropical Diseases
BCC	Behaviour change communication
CDD	Community drug distributors
CBM	Christian Blind Mission
FGD	Focus group discussion
IEC	Information, education and communication
IMA	Interchurch Medical Assistance
IOM	International Organization for Migration
M&E	Monitoring and evaluation
MDA	Mass drug administration
MoH	Ministry of Health
NGO	Non-governmental organization
NTDs	Neglected tropical diseases
PHCC	Primary healthcare centre
SDG	UN Sustainable Development Goal
WHO	World Health Organization
WASH	Water, sanitation and hygiene

Need for a harmonized strategy

South Sudan has a high burden – among the highest in sub-Saharan Africa – of neglected tropical diseases (NTDs). This adversely affects the health and social and economic well-being of people in the country. The prevention, control and eventual elimination of many NTDs depend heavily on improved access to water, sanitation and hygiene (WASH) and, once there is access, on sound sanitation and hygiene practices. This is especially the case in NTD endemic communities.¹

The main NTDs prevalent in South Sudan include lymphatic filariasis, schistosomiasis (bilharzia), soil-transmitted helminths (STH), onchocerciasis, trachoma, leishmaniasis and Guinea-worm disease.

While the Ministry of Health (MoH) of South Sudan, through its NTD programme, had prioritized NTD/WASH partnerships and collaboration to improve the national NTD response, the programme lacked resources, capacity and a technical framework to lead the development of a harmonized NTD/WASH communication strategy.

In 2019, the NTD team reviewed the existing behaviour change communication (BCC) NTD strategies and materials in South Sudan, which revealed a lack of focus on WASH as an NTD prevention approach. In addition, all BCC materials targeted a specific disease or behaviour, which is against evidence that shows that NTD messages integrated with sound WASH practices can reduce the burden of various NTDs that affect the country. In consultation with the main WASH and NTD actors in South Sudan (see Annex 1 and 2 for a full list of actors involved), the MoH, supported by Ascend, initiated an interactive process to develop an integrated NTD/WASH communication strategy focusing on multiple NTDs and to revise the related BCC materials.

Ascend aimed to (re)activate new and existing coordination mechanisms between WASH and NTD stakeholders in South Sudan to build on existing policies and strategies, and to develop a harmonized approach to fight against NTDs in the country. This will prioritize the provision of WASH interventions in communities, schools and health facilities in endemic areas where access to WASH is limited but essential to sustain and consolidate the gains made in medical treatment.

In addition to the lack of WASH and NTD integration, previous BCC materials were developed without consulting the communities – the beneficiaries. In line with best practices, the Ascend team developed new tailor-made NTD communication material based on the needs

community members expressed during a comprehensive pre-testing process with representatives in the target communities. It is widely documented that involvement and engagement of the target communities in programmes can increase the impact of health and development programmes and lead to sustainability.³ Despite being a widely acknowledged best practice, beneficiary input for BCC

Box 1. Key data sources

Desk review:

- NTD/WASH national master plan
- NTD/WASH BCC strategy
- BCC guidance documents
- existing BCC materials
- BCC consultant reports
- NTD/WASH framework
- the South Sudan national health policy

In-depth interviews² with 13 stakeholders representing:

- Ministry of Health (2)
- Ministry of General Education (1)
- Ministry of Water Resources and Irrigation (1)
- international and national NGO (6)
- community leaders from Juba county and Bentiu (2)
- health worker in a primary healthcare centre in Juba (1)

¹ Freeman MC, Ogden S, Jacobson J, Abbott D, Addiss DG, et al. (2013). Integration of Water, Sanitation, and Hygiene for the Prevention and Control of Neglected Tropical Diseases: A Rationale for InterSectoral Collaboration. *PLoS Negl Trop Dis* 7(9): e2439. doi: 10.1371/journal.pntd.0002439

² Verbal consent was obtained from all the respondents before interviews. Written consent was obtained from the health workers in the facilities for them to participate and to be photographed.

³ Tapia, M., Brasington, A., & Van Lith, L. (2007). *Involving Those Directly Affected in Health and Development Communication Programs*. Baltimore: Health Communication Partnership based at the Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs.

material development is rarely collected or documented, potentially due to the challenges and time constraints that projects often face.

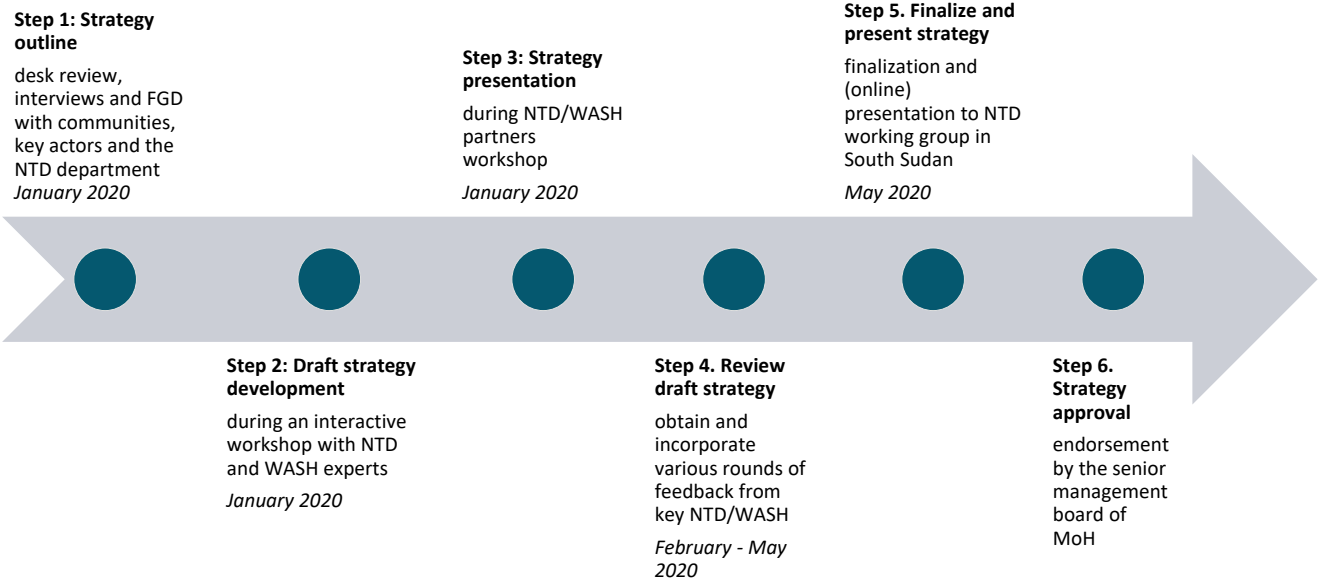
This learning brief documents the interactive process undertaken to develop the communication strategy and related communication material in South Sudan. To gain a broader understanding of the process and lessons learned, we reviewed the relevant documentation and material, and conducted in-depth interviews with people who were involved in the process: 13 NTD and WASH stakeholders representing governmental institutions, NGOs, community members and health workers (Box 1). Information provided in this brief can guide other organizations aiming to develop a comprehensive and integrated NTD communication strategy and relevant BCC materials for communities in a similar setting.

Development of a new communication strategy

To ensure the sustainability, ownership and continued development of appropriate BCC material for communities, the MoH NTD programme, with strong endorsement from the MoH senior management board, led the development of the harmonized NTD/WASH BCC communication strategy. The process was supported by an Ascend communication consultant, the country team, and the Ascend BCC and WASH regional experts.

Figures 1 and 2 provide an overview of all the steps taken during the participatory development of the communication strategy and the subsequent development of the communication materials.

Figure 1. Steps in development process of the communication strategy



The NTD programme team and the Ascend BCC consultant developed the communication strategy outline with input from the Ascend regional BCC and WASH leads. The outline was based on information derived from desk reviews of the national NTD strategy, existing BCC material, publications from international organizations, best practices around communication and any other relevant material.

Another important part of the outline development came from details gained from interviews and focus group discussions (FGDs) with the community members and others already working in the sector or with experience in community BCC messaging.

Following this, in January 2020, a core writing team of 15 participants (selected in collaboration with the MoH NTD programme manager) drafted the communication strategy using the consultant’s

content outline. The core team was composed of stakeholders operating in the area of NTDs in South Sudan (see Annex 1), who reviewed the existing BCC messages on WASH and NTDs and identified what could be adapted or adopted and where new messages were needed.

The draft strategy document was then presented at a three-day NTD partner collaborative workshop in Juba between 28 and 30 January 2020 to review the draft strategy and provide revision suggestions based on their broad experience of the sector and the issues specifically affecting South Sudan. Thirty-one participants from a wide variety of organizations, government departments and NGOs (see Annex 2) attended the workshop. To ensure involvement of all stakeholders in the process, the national NTD technical working group and other partners were given a chance to provide input and review each draft of the strategy. This **created a unique open environment and increased the sense of stewardship** among stakeholders under the guidance and leadership of the MoH and governmental departments.

“ I am very impressed by the process and found it very insightful. All relevant ministry officials and stakeholders were effectively engaged in the process.” **Lead consultant**

Development of communication materials

As shown in figure 2, the process consisted of six steps taken between June 2020 and March 2021. First, a sub-group of the national NTD technical working group held a **prioritization exercise** with key stakeholders aiming to select types of messages and priority audiences. The participants of this online exercise selected the most pressing communication needs among the many described in the communication strategy.

Next, the Ascend national consultant developed **creative briefs** for the project partners to review. Staff from Health Promotion Department and the Ascend country team **discussed message concepts with community members** to ensure the messages were relevant to their needs, that the situations described were recognizable and that the recommended practices were feasible.

For the first time in South Sudan, people from the communities had been consulted in the development of communication messages. This is an important step in the

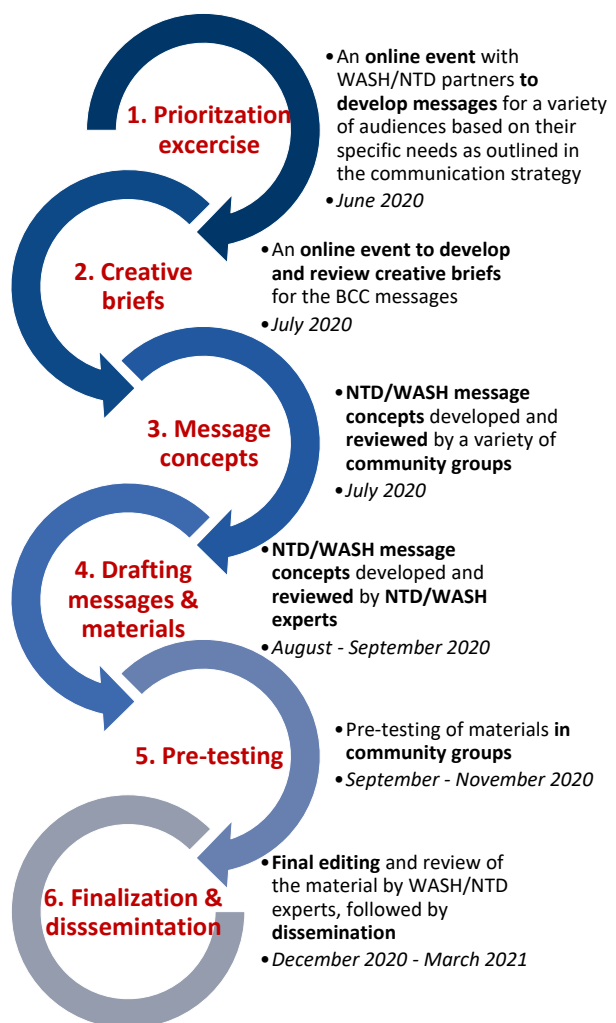


Figure 2. Steps in development process of communication materials

recognized best practice⁴ for the development of BCC material and should involve a broad spectrum of community members by income, gender and age.

In the next step, the national NTD technical working group and staff from the Health Promotion Department supported by Ascend and using feedback received from the communities **drafted the main communication messages and materials**: a flipchart for health workers, a teachers' guide, a community leaders' factsheet, an NTD/WASH communication guide and posters.

Staff from the Health Promotion Department together with the Ascend country team subsequently **conducted the pre-testing** of the materials to solicit input from the community members. To address the lack of experience the staff from the Health Promotion Department had in conducting pre-testing, Ascend held an online training course and provided a detailed guidance document.⁵ Pre-testing was carried out in Juba and Bentiu. The team conducted four sessions with different target groups: men, women, youth and community leaders. This process ensured that the communication material was tailored to the needs of the specific audiences. The team developed interactive material, with participatory activities that facilitate the internalization of messages among the intended audiences.

Local leadership driving partnership and collaboration

Partnership is crucial to achieve NTD control, reach elimination targets and to ensure the long-term impact of the programmes.⁶ The MoH NTD department's pro-active role in bringing together those involved in the NTD and WASH sectors in the country, supported by the Ascend country team, resulted in a highly participatory strategy development process. The NTD manager was already involved in WASH meetings and therefore able to mobilize WASH partners. The government led the full process, culminating in the MoH's senior management board endorsing the NTD/WASH communication strategy.

“ We [the NTD Department and Ascend] brought together stakeholders from health and WASH to discuss ideas and what was to be done; analyse the gaps and customize the communication strategy and tools.” **Dr Samuel Makoi, NTD programme manager, MoH**

Through this process, valuable NTD and WASH expertise was brought together to develop a comprehensive NTD/WASH communication strategy and communication material. By involving actors in all steps along the process, we established a sense of team ownership.

During the consultative meetings, stakeholders extensively discussed the links between the NTD and WASH sectors and possible ways for collaboration. As part of the meetings, stakeholders reviewed each other's existing BCC material related to NTDs or WASH and made recommendations on how to harmonize these messages. Partners felt that this exercise was a “game changer” and “an eye opener” contributing to success.

“ Participation in this exercise has widened my understanding of health issues, and now I can advocate for a change of curriculum. As I am reflecting on this, in the next curriculum review, I will advocate for the integration of NTD and WASH. Currently, our curriculum teaches diseases and WASH elements separately. There is nothing about NTDs.

⁴ Jessica Fitts Willoughby & Robert Furberg (2015). Underdeveloped or Underreported? Coverage of Pretesting Practices and Recommendations for Design of Text Message-Based Health Behavior Change Interventions, *Journal of Health Communication*, 20:4, 472-478

⁵ Ascend (2021). Guide for Pretesting NTD/WASH Communication Messages and Materials

⁶ World Health Organization (2018). WASH and Health Working Together: a 'How-To' Guide for Neglected Tropical Disease Programmes. Geneva. License: CC BY-NC-SA 3.0 IGO

The Ministry of Education should promote awareness in schools, and talk about NTDs and WASH practices. They say if you want to end a practice, do it through schools, model the kids as they grow and outgrow a generation. That way, a new behaviour is adopted in a community.” **Mr Sokiri Charles, Ministry of General Education & Instructions**

Several partners appreciated the timing and need for collaboration.

“*I totally agree that this strategy harmonizing NTD/WASH/BCC was developed at the right time when there was a huge gap in programming. These two interventions [NTDs and WASH] were running in parallel.”* **Respondent from a local organization**

Some participants expressed appreciation for the fact that the process also triggered discussion on the meaning of collaboration and integration and ways to take it forward.

“*Our document started by defining the words integration and collaboration. We need to be clear when we use this word integration. We need to link this to NTD indicators and SDG 3.3 targets and actively engage WASH partners to use NTD indicators to prioritize WASH resources.”* **Dr Samuel Makoi – NTD Programme Manager MoH**

As a result of the discussion process, some partners working at the community level on a single NTD, such as trachoma or schistosomiasis, concluded that they could employ a more integrated approach to address multiple WASH-related NTDs. Participants agreed that effective integration between WASH and NTD control likely increases community capacity for the adoption of WASH practices, thereby reducing NTD risks.

Due to the COVID-19 pandemic, most meetings took place virtually. Although partners experienced challenges with internet connections, virtual platforms were a good alternative to continue engaging with all those involved.

Focus on WASH-related NTDs

Overall, those involved with the development process found that the NTD/WASH BCC communication strategy was well aligned with national NTD priorities and the NTD Master Plan. Some of the respondents recommended a further review to ensure the communication strategy remains aligned to the master plan and the NTD/WASH framework, which are both currently being developed.

“*I believe the NTD/WASH BCC strategy is well aligned to the master plan and well done. At this stage, we only need an independent review to tell us if it is aligned or not.”* **Respondent from an international NGO**

Focusing on WASH-related NTDs was an important aim in the development of the communication strategy, and WASH partners expressed their excitement about integrating NTD control messages into the existing WASH communication interventions. Stakeholders acknowledged the missed opportunity of not integrating NTD education messages into existing WASH programmes. Through the process of strategy and material development, the stakeholders shared the added value of focusing on WASH-related NTDs, especially for WASH partners who have partners implementing WASH services at the community level. Prioritizing WASH-related NTDs and implementing the NTD/WASH BCC strategy will improve the outcome of the NTD control programme, strengthen the collaboration and minimize missed opportunities. Some of these interventions are funded already

and may not require additional funding but require only the continued guidance and leadership from MoH on how to integrate and affect the NTD response.

The communication strategy and the related BCC materials met the expectations of most of the stakeholders interviewed. However, as the communication strategy prioritizes NTDs for which recommended WASH practices are crucial, some were disappointed that other NTDs were not included.

“Overall, this strategy document is very good and meets our expectations. However, the strategy was mostly focused on NTDs related to WASH. Our main focus in visceral leishmaniasis. So, with a lot of focus on WASH and related NTDs, I feel VL is left out of this document.” **Respondent from an international NGO**

Importance of pre-testing and community engagement

The positive effect of the meaningful engagement and participation of affected communities in the development of health and communication interventions has been documented earlier and has been found to contribute to long-term sustainability⁷. In South Sudan, community engagement took place in various steps of the process (figure 2), including the pre-testing of materials.

In the consultative meetings, all stakeholders reviewed existing communication materials and identified existing gaps. A total of 21 new communication materials were developed (Table 1). These new materials target different groups: caregivers and families, community members, heads of households and schoolchildren. Communication materials were developed for direct use and through interaction with community leaders, schoolteachers and health workers. Below we provide examples of identified gaps or limitations related to old materials and the solutions offered:

- Some materials **did not exist**. For example, there were no materials for community leaders to inform and motivate their community members on how to prevent NTDs. There is now new material to fill in this gap.
- Old materials were informative, but **not appealing**. For example, communities could not relate to the images and most posters were text heavy. The team made the images more appropriate by collecting feedback from beneficiaries. For example, communities advised that a caregiver in one picture uses her right hand for washing her child's face instead of her left hand and to have her wearing slippers or shoes (figure 3).
- Most of the old materials were targeted at the general public, which made the materials **less appropriate to specific audience** categories. The new materials are more visual and address a specific audience (for example, schoolchildren, caregivers, household heads). There are plans to translate the materials into Arabic.



Keeping your child's face clean reduces the risk of trachoma and other diseases of the eyes

Figure 3. A poster for caregivers

⁷ Tapia, M., Brasington, A., & Van Lith, L. (2007). Involving those Directly Affected in Health and Development Communication Programs. Baltimore: Health Communication Partnership based at the Johns Hopkins Bloomberg School of Public Health/Centre for Communication Programs

- d. Materials provided information but were **not actionable**. Messages in the new materials (especially posters for the communities) are clearer and actionable, ensuring that actions are feasible for local communities.
- e. The old materials **did not reflect any link between WASH and NTDs**. Information on soil-transmitted helminths was very limited. New materials link the different NTD diseases to sanitation.
- f. The old material was **directed primarily to community members**. The new material includes guidance for key groups involved in community information and mobilization, such as teachers, community leaders and health workers on how they can actively engage in discussions with communities and children to improve WASH practices and prevent NTDs.
- g. School materials were **passive**, the teacher was expected to provide monologues of information to pupils. The new interactive material for schools include several informative games children can play. A detailed teacher’s guide (figure 4) explains how to conduct interactive exercises with pupils.
- h. Some material **integrated COVID-19 messages**, providing clarity on conflicting information regarding face washing for COVID-19 and trachoma.

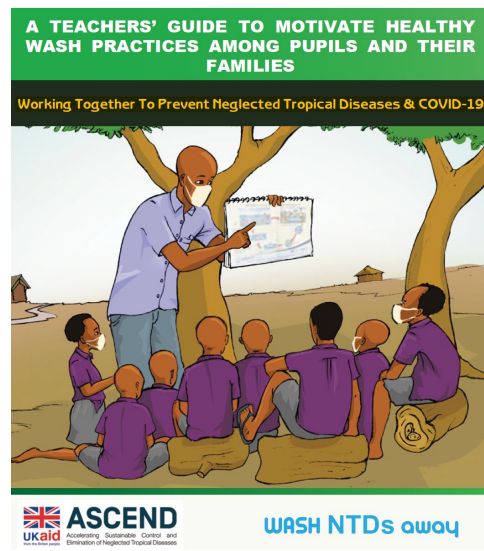

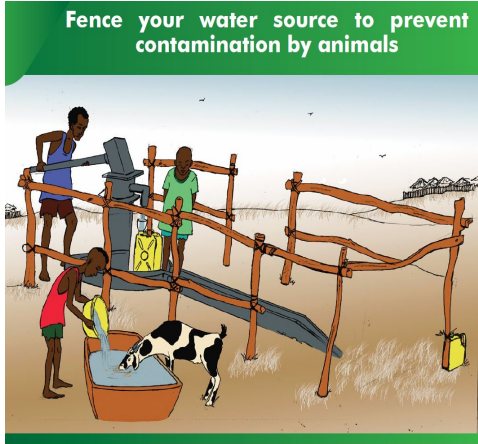


Figure 4 A teachers' guide

👏👏 *We consulted the Hygiene Hub on best ways to integrate conflicting messages ‘wash your face’ relevant for trachoma and ‘don’t touch your face’ relevant for COVID-19.” Ascend country lead*

Table 1. Overview of new BCC materials

Material type	Short description
Community leader fact sheet	This guide provides facts for the community leaders to help them motivate their community members to take action and prevent NTDs and improve health.
School education material. Teachers guide	This guide supports teachers to motivate pupils to take up sound WASH practices to prevent NTDs and COVID-19 in schools among pupils and their families. Includes information to be delivered and methods (instructions for games, interactive discussions with children of different age groups).
Health workers’ job aid	A community education flipchart designed to support health workers to discuss – in an interactive manner – the importance of WASH practices, such as latrine use, hand washing and facial cleanliness These are practices that caregivers can adopt to protect themselves and their children from NTDs and other related infections. It helps caregivers to focus on achievable practical changes they can make.

<p>Community education material. A set of 18 posters for community members and caregivers</p>	<ul style="list-style-type: none"> • Poster for families and caregivers on the risks of open defecation. Provides information on bilharzia and trachoma and how open defecation increases everybody's risks to infection. • Poster for community members and caregivers on bilharzia and how to protect themselves and children from infection. • Poster for community members on the importance of handwashing, face washing and a clean home to prevent NTDs (trachoma, bilharzia), cholera and other diseases. • Poster to encourage communities and families to use latrines for privacy and convenience. • Poster to encourage community members to use latrines and keep them clean from flies, which carry trachoma and other germs. • Poster targeting caregivers and families on safely disposing of children's faeces into latrines to keep flies away. • Poster for community members on the importance of fencing water sources to keep animals away to prevent diseases like trachoma, bilharzia and cholera. • Poster for heads of households and families to take responsibility for their own health and ensure the use of latrines and their cleanliness. • Poster on the risks of open defecation and importance of latrines for community members. Provides information on trachoma, bilharzia, cholera and other diseases. • Poster for caregivers and families provides information on the risks of open defecation and how it can increase children's risk to trachoma and other diseases. • Poster for caregivers and families and schools on how children can become infected with bilharzia through contaminated water sources. • Poster for caregivers and families on the importance of face washing with soap for children to prevent trachoma and other related diseases. 	 <p>Always wash your hands with safe water and soap after using a latrine</p> <p>To prevent trachoma, bilharzia, cholera, COVID-19 and related diseases</p>  <p>Fence your water source to prevent contamination by animals</p> <p>To protect you from diseases such as trachoma, bilharzia and cholera</p>
<p>School and community education materials</p>	<ul style="list-style-type: none"> • Poster for communities and schools on preventing trachoma, cholera, bilharzia and COVID-19 through hand washing using water and soap. • Poster for caregivers and schools on critical moments to wash hands with soap to protect from NTDs and WASH-related diseases. 	

The experience of such pre-testing was unique for both the MoH health promotion team and community participants. The participatory process brought a lot of excitement and commitment and encouraged community members to freely express themselves and reflect on their situation. MoH team members reported that it was new, interesting and very enlightening for them to go through all the stages of BCC material development, starting from message development and presentation of concepts to engaging in community feedback and final adaptations.

“ This process is different this time. Usually BCC materials are brought here to MoH ready for us to use. This is the first time I have taken materials to the community for pre-testing and developing with community members based on their needs. They are likely to adopt and use these messages to improve their lives. I was happy that we partnered with the community in

this NTD/WASH BCC material development. It was a costly exercise, but a very important one for the people whose lives we want to affect. And they felt part of the planning for their own health for the first time.”

Sarah Nyibak – MoH Department of Health Education and Promotion.

Community leaders involved in the pre-testing of the materials designed for them (the community leader factsheet) appreciated the materials and confirmed that they addressed an important gap in their information on NTDs and WASH. Knowledge on NTDs and WASH is particularly important to community leaders as they play an important role in the social mobilization of community members for NTD and WASH interventions.

“ You have done a good job with these BCC materials; nobody can do such work and process, only those who love this country. And a lot of effort has gone into this now. Good materials. We are now well informed and aware of NTDs and WASH.” **Chief of Lemon Gaba area, Juba.**

“ I like this community factsheet after all the feedback from the community leaders, and I see a great guide for us. I just read through some of the pages and it is very good ... The pictures now look like us and even the home environment. I can say we relate to what is happening in these pictures.” **Community leader from Lemon Gaba area, Juba.**



Figure 5. Meeting with Community leaders in Juba (left) and discussions with a women’s group of community members in Bentiu (right)

Health workers also appreciated the new education material. The health workers’ flipchart serves as a tool in teaching sessions with community members visiting the health centre or for health promotion during outreach activities. Health workers found the flipchart easy to use with patients. It was relevant and appropriate, but they indicated the need for information in Arabic.

“ This is a good tool for us to use during our health education sessions with the clients. It provides a good guide for discussion during sessions. However, I would prefer to use an Arabic language version because I am more comfortable using Arabic than English.” **Health worker at Kator Primary Healthcare Centre, Juba**



Figure 6 Health workers in Kator PHCC on World Water Day 22 March 2021

This experience reiterated the importance of involving stakeholders from different sectors, such as WASH, NTD and community members to effectively address NTDs.

“ From previous experience, we know that communities are not informed about NTDs and treatment coverage is limited ... we see communities sometimes refuse to take medication. So we thought it was time to strengthen social mobilization and communication, bringing together the community, WASH partners and NTD sector professionals. If we leave WASH out, the NTD targets will not be achieved.” **Mr Sokiri Charles, Ministry of General Education and Instructions.**

Conclusion

Through this participatory process, stakeholders had a first-hand experience of community engagement in the development of communication material. All agreed that **this process helped make these materials more relevant and better suited to the needs of community members.** In addition, people involved in the process now have **practical experience to conduct similar engagement processes** and have access to guidance documents developed to support and replicate the procedure for the development of other communication material.

“ The process made all partners realize that involvement of the target population in the development of communication materials is essential for future communication efforts. I believe South Sudan now has a comprehensive strategy on NTD/WASH, and BCC materials will address the gaps. This is a key milestone to the South Sudan NTD programme.” **ASCEND country lead**

By building local capacity in the implementation of best practices, we can improve the chances that participatory processes will become more widely practiced.

Our experience provides evidence that it is **possible to effectively engage communities, even in a fragile environment.** It also shows that the **community members appreciated** being part of the process, instead of the communication messages coming from the top down only. Their input into

the development of the material was invaluable to making the situations recognizable and actionable in their community settings.

Annex

Annex 1. Representatives of the following organizations contributed to the draft of the communication strategy

AMREF Health Africa
Interchurch Medical Assistance (IMA)
Carter Center
World Health Organization (WHO)
MoH NTD Programme staff team
MoH Health Promotion & Education Department
Ministry of Irrigation and Water Resources of South Sudan
World Vision
MENTOR Initiative

Annex 2. Representatives of the following organizations attended the workshop to review the draft communication strategy

Ministry of Health
Ministry of General Education and Instructions
Ministry of Gender, Social Welfare and Religious Affairs
Ministry of Water Resources and Irrigation
WHO
UNICEF
AMREF
IMA
International Organization for Migration (IOM)
International Rescue Committee (IRC)
MENTOR Initiative
World Vision
ONO AID
Ascend
Norwegian Refugees Council (NRC)
Health Pooled Fund (HPF)
Christian Blind Mission (CBM)
University of Juba,
Malaria Consortium
Carter Center

Annex 3. List of Interview respondents

S/N	Position	Organizations
1	NTD programme director	Ministry of Health
2	Health promotion officer	Ministry of Health
3	Ascend programme lead South Sudan	Crown Agents
4	BCC consultant	Consultant
5	WASH/NTD manager	AMREF Health African
6	Executive director	ONO AID
7	Communication officer	IMA World Health
8	Senior technical advisor for trachoma	Carter Center
0	Director general	Ministry of Water Resources and Irrigation
10	Director for post schools programme	Ministry of General Education and Instructions
11	Community representative (audience)	Lemon Gaba area
12	Community leader	Lemon Gaba area
13	Nurse/health worker	Kator PHCC