Collecting stories about neglected tropical diseases
A beginner's guide to field communications
Foreword

This toolkit provides practical guidance to Neglected Tropical Disease NGO Network (NNN) members to collect content and tell the stories of people affected by NTDs.

The toolkit was created by members for members following NTD community feedback at the ‘Telling the NTD Story’ workshop at the 2018 NNN conference in Addis Ababa and is a testament to the increasing engagement among NTD stakeholders to support each other for a world free of NTDs.

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For more information visit: www.ntd-ngonetwork.org.

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Stories by and about people affected by neglected tropical diseases (NTDs) are essential to raise public awareness and mobilise donor support.

This toolkit provides guidance for non-communications staff to collect valuable content for stories that will benefit communities affected by NTDs.

Collecting stories is a vital part of our work

Photo: Michael Amendolia/The Fred Hollows Foundation
Where are the stories used?

The stories and content you collect could be used in:

- Television, newspapers, blogs and online articles at national, regional and global levels
- Social media campaigns
- Fundraising campaigns and appeals
- Advocacy materials
- Reports and other publications
What makes a story successful?

NTD stories should help the reader understand what people affected by NTDs experience. All stories should consider:

**Vulnerability and challenges:** Poverty, discrimination, a lack of education, stigma, social exclusion and difficulty in accessing health services can make people feel vulnerable. Can you show the impact NTDs have on peoples lives?

**Anxiety:** Poor access to health services can cause anxiety about NTD programs and interventions. This can include fear of taking medicines or undergoing surgery. Can you show the perspective of affected people?

**Hope:** Access to NTD services can alleviate pain, disability and associated stigma, giving people the hope that they will be able to be active and productive members of their family and community. Can you show how people feel?

**Dignity:** People affected by NTDs deserve respect. NTDs are diseases of poverty and marginalisation and NTD stories should be careful not to damage the dignity of the persons affected. Be sure to treat all people with understanding and tell stories in an authentic way.

Photo: Maha Adams/The Carter Center
Preparing for the story

- Always ask for permission before conducting an interview or taking photos/video
- Ensure people know that access to interventions is not dependent on them agreeing to an interview
- Explain the purpose of interviews, photographs and video (for example: to develop materials for community awareness and fundraising purposes, so that more people can receive NTD interventions)
- Obtain consent for all people you interview in line with your organisation's consent policy (this is usually done with a consent form). Consent can be withdrawn by individuals even after materials have been collected
- Prepare a checklist that includes when and where an event occurred happened and who was involved
- Remember "who, what, where, when and how" are the critical questions to answer in any story. Think about your audience!

See Annex 1 for a checklist to help with your communications preparations.
CAUTION!

Check your organisation's policies!

Please refer to your organisation's policies on safeguarding and data protection. Take care to protect the rights and safety of the people you're working with, especially children or vulnerable people.

It might be the case that full names are prohibited alongside other identifiers such as age or the name of the persons village or community. In other cases, organisational policies might state that children cannot be interviewed alone. This is extremely important so please do check with your communications teams for further guidance.
Capturing voices from the field

Quotes are an important part of communicating our work. Quotes bring stories to life by directly connecting the audience to key personalities. Quotes can be used for all sorts of communications outputs so it's important we get good quotes and lots of them!

Photo: Marcus Perkins/GSK
When we tell the story of a person affected by NTDs, it’s important to ask questions that show their personality and paint a picture of what life is like for them. You are capturing their story and it’s important that their perspective is heard.

To ensure content can be used effectively, have the person repeat the question as part of their answer as short answers are hard to quote.

For example:

Question: When did you start to lose your sight?
Answer: "Last week."

Question: When did you start to lose your sight and what changes did you notice?
Answer: "I started to lose my sight last week. At first, my eyes were sore and then things became blurred."
Getting good quotes

Ask questions that encourage descriptive answers. Don't ask questions that require “yes” or “no” answers or questions that only need one or two-word answers. Ask questions that will encourage the patient to tell their story.

Remember:
• Follow up questions are very important! Make sure you listen to the answers so you can ask follow-up questions
• Record the interview on your phone so you can talk freely rather than scribbling down notes
• Make sure to get permission to record. Before you leave, check if the recording has worked

See Annex 2 and 3 for example questions you can ask.
Getting good photos

Strong images show NTD work and inspire people to take action. As the saying goes: "a picture tells a thousand words". Photographs work by:

- Creating an emotional response
- Providing context to the story
- Helping people connect with patients they will never meet
- Bringing a story to life!

What photos are we looking for?

We are looking for strong images that show our work and inspire people to take action. Photos should:

- Be simple and well balanced
- Make sense to people who weren’t there
- Convey a story, emotion or message
- Convey the scene/subject

Make photos tight, bright & light!

- **TIGHT**: Tightly crop your photo on the main subject, with minimum background distraction
- **BRIGHT**: Make your photo bright and colourful. If necessary, increase the exposure
- **LIGHT**: Photos should have a positive tone. Try to capture uplifting photos rather than sad or artistic photos
How can we get good photos?

Be patient in establishing a connection
People may be hesitant to interact with you at first. Understand that they're going through a difficult time. Once a relationship has been established and a photo is taken, show it to them and offer to share the photo with them via mobile if possible (or take a polaroid camera with you as well so you can give them a photo to keep).

Take a mix of photos
Posed portrait shots with people affected by NTDs against a relevant background like the family home or village can help to connect the audience to the story. However, 'action' shots that show people doing everyday activities can make the stories more relatable to the audience. Let people act naturally and forget about the camera. Documenting children interacting with their parents, people cooking or interacting in their community will help to show what life is like for them.

Be prepared and plan ahead!
What kind of shots do you want to see? What camera settings should you have to achieve that kind of shot? Don't be afraid to use an automatic setting if you're not confident with a camera.
What photos should we avoid?

- A poor image is one with too much going on, where everything is vying for the viewer’s attention
- Photos of meetings or staged large group shots are generally less interesting
- Photos that are overly moody or artistic
- Photos of children who are partially clothed

What camera should I use?

What a picture shows can be more important than the quality of the image. A well composed photo taken on a smartphone, along with a caption to explain the image, can make a fantastic social media post. Don’t worry if you left the “good camera” at home!

Should we get videos?

Photos should generally take priority, but you may also take a video using your smartphone. These raw videos may be used on your organisation's social media pages. If you are taking photos, hand your smartphone to someone else to take a short video.
Annex 1: Field communications checklist

- Talk to communications staff at your organisation about your work
- Plan who you want to interview and photograph
- Ensure you have equipment to take photos and record interviews
- Prepare a checklist with interview questions and other desired content
- Ask your organisation for consent forms
- Ensure people are comfortable being interviewed and photographed
- Provide consent forms to all people interviewed or photographed
- Ensure quotes gathered include the question asked
- Ensure photos are tight, light and bright!
Annex 2: Sample questions for people affected by NTDs

Personal questions
• What is your name and how old are you?
• What is your family like?
• What do you do for work?
• What is your favourite pastime?
• How are you viewed in the community?

Health-related questions
• When did you start to notice symptoms?
• What does the doctor/nurse/medical staff say about your disease and how does this make you feel?
• What health services do you have access to?
• How far is the nearest clinic/hospital?

Questions about living with NTDs
• How has your everyday life been affected?
• How has your work life been affected?
• How have your family and social life changed?
• What do you want to do after you receive treatment? What is the first thing you will do? How will having treatment change your life?
• How will eliminating this disease benefit you, your family and your community?
Annex 3: Sample questions for field staff

Personal questions

- How long have you worked as a (doctor/nurse/community health worker)?
- Why did you become a doctor/nurse/community health worker)?
- Can you describe the training you received?
- What do you want to learn in the next stage of your training?
- How has this training helped to reduce the prevalence and effects of NTDs?
- Why do you like working in this field? What does it mean to you and the communities you help?
- How do you build trust with patients and the community?
- Why did you choose to work in NTDs?
- Is there one example of a person you have helped that stays in your memory?

Health questions

- What are the characteristics of people affected in this area such as age, gender, economic status?
- What are the most common health problems in this area?
- What are the biggest challenges to implementing health interventions in this area?

Questions about communities with NTDs

- What impact do NTDs have on the communities you serve?
- How will eliminating NTDs benefit the communities you serve?
- What more needs to be done to provide health services to people affected by NTDs?