

Stakeholder Engagement

How do communities make informed decisions about our work?



Stakeholder engagement is essential to Target Malaria, reflecting its core values of co-development, openness and accountability. Engagement takes various forms and has different objectives, including co-developing a better technology with stakeholders.

Part of this engagement also aims at ensuring that communities can make an informed decision about project activities and that these decisions are recorded. At each phase of our technology development, we are committed to work closely with local participating communities to ensure that no activity goes ahead without their agreement.

Beyond the moral and ethical imperative for engagement and informed decision, the project believes that co-developing this technology with local stakeholders will ensure that local knowledge is integrated to improve it and help ensure its agreement.

Why do we need communities to make informed decisions?

Target Malaria is committed to engage communities and ensure that they take part in decisions concerning our activities in their village or neighbourhood.

Ethics committees at different levels – national level, project level and partner institution level – are paying particular attention to ensure that this research is done according to ethical standards. The institutional ethics committees review all the research protocols involving communities and individual participants, and no field activities take place without their prior approval.

What is the difference between informed consent and informed community agreement?

The concept of consent is well established and refers in most cases to an individual informed decision for an activity that involves a person or a household, as part of a clinical trial. When Target Malaria collects mosquitoes from individuals' bedrooms, prior informed consent is required before any activity can take place.

However, when considering an activity taking place at a community level, the concept of prior individual informed consent is inadequate (WHO¹, Kolopack and Lavery²). Area-wide interventions call for a different type of consultation and agreement, which is a community level informed agreement (also called authorization, Neuhaus and Caplan³). Target Malaria seeks informed community agreement for all community level activities.

How are individuals and communities informed before making a decision?

A process of knowledge sharing is the basis of Target Malaria's engagement strategy. This process recognises that both the project and the communities have information to share. The project provides information about the proposed activities, including potential risks and benefits, and the expectations regarding the community. The content of this information sharing is reviewed and approved by institutional ethics committees. This process goes back and forth to ensure that all the questions and concerns from communities, as well as their own knowledge, have been taken into account and addressed by the project.

How was the decision on the agreement model made?

There are many different ways of asking and recording informed community agreement. Target Malaria decided not to make the decision of what would be appropriate, but rather through engagement with communities, asked them to design what would be appropriate considering their social and cultural context. A dialogue was established early on to agree on a set of principles – transparency, inclusiveness, gender and minority representation, openness to different perspectives – and communities elaborated their agreement models. As a result, the process to reach a community decision and to record this decision varies between countries, while still following the same guiding principles.

For example, in Burkina Faso, the community in the villages decided to establish a reference community group, representing the whole community and that communicates the community decision to the project, after their consultation. On behalf of the community, they are in charge of signing an agreement form, accompanying the information sheet summarising the activity proposed.

In each country, the agreement model proposed is submitted to the institutional ethics committee to ensure that what is proposed is aligned with ethical principles.

On what activities/steps do communities express their opinion?

At Target Malaria we seek consent and/or community agreement for:

- **Entomological collections**
Target Malaria conducts a variety of entomological activities that involve collecting mosquitoes from various villages. Based on the information provided, household representatives are invited to consent for in-house collections, and village representatives to express community agreement more broadly.
- **Work under containment**
Contained work in our laboratories is an important phase of our work. Before we are able to import mosquitoes into our laboratories in Africa, we require approval from national regulators, who assess the application proposed and ensure that the facility meets all the containment requirements before making any decision. The project decided voluntarily that agreement from the communities surrounding the laboratory was important. When surrounding communities feel they have been informed and their questions have been adequately addressed, the project asks them to make a collective decision about the contained work.
- **Small-scale releases**
In each stage of development of the technology we propose to conduct small-scale releases. These releases take place in villages where the project has been present with field entomological collections. The small-scale releases depend on the approval of the national authorities where we work. Along with the regulatory process, Target Malaria also asks the communities if they approve the small-scale releases proposed.

- 1 WHO, *The Guidance Framework for Testing Genetically Modified Mosquitoes*, WHO/TDR, 2014
- 2 Kolopack and Lavery, *Informed consent in field trials of gene drive mosquitoes*, Gates Open Research, 2017
- 3 Neuhaus and Caplan, *Ethical lessons from a tale of two genetically modified insects*, *Nature Biotechnology*, 2017