

Explaining the continuing high prevalence of trachomatous trichiasis unknown to the health system in evaluation units: a mixed methods explanatory study in four trachoma-endemic countries

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Background: We explored reasons for continuing higher-than-anticipated prevalence of trachomatous trichiasis (TT) unknown to the health system in population-based prevalence surveys in evaluation units where full geographical coverage of TT case finding was reported.

Methods: A mixed-methods study in Ethiopia, Kenya, Nigeria and Tanzania was conducted. We compared data from clinical examination, campaign documentation and interviews with original trachoma impact survey (TIS) results.

Results: Of 169 TT cases identified by TIS teams, 130 (77%) were examined in this study. Of those, 90 (69%) were a match (both TIS and study teams agreed on TT classification) and 40 (31%) were a mismatch. Of the 40 mismatches, 22 (55%) were identified as unknown to the health system by the study team but as known to the health system by the TIS team; 12 (30%) were identified as unknown to the health system in the TIS team but as having TT by the TIS team; and six (15%) were identified as unknown to the health system in the TIS team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team but as known to the health system by the study team based on documentation reviewed.

Conclusions: Incorrectly reported geographical coverage of case-finding activities, and discrepancies in TT status between TIS results and more detailed assessments, are the key reasons identified for continuing high TT prevalence.

Keywords: mismatch, survey, trachoma, trachomatous trichiasis.

Introduction

Trachoma is the leading infectious cause of blindness worldwide, caused by ocular infection with *Chlamydia trachomatis*. With repeated infections, it can cause trachomatous trichiasis (TT), which is defined as at least one eyelash from the upper eyelid touching the eyeball, or evidence of recent epilation of in-turned eyelashes from the upper eyelid.¹ It can cause damage to the cornea with extreme pain and, if left untreated, can lead to irreversible vision loss and blindness. Those with advanced stages of the disease need surgery to correct their in-turned eyelashes and prevent further damage to the eye.² Based on June 2022 data, 125 million people still live in trachoma-endemic areas and are at risk of blindness due to trachoma.³ Africa is the most affected continent, with 25 countries known to require intervention to achieve elimination of trachoma as a public health problem. Globally, there are an estimated 1.7 million people with TT needing management.³

One of the WHO criteria for a country to be validated as achieving trachoma elimination as a public health problem is demonstrating a prevalence of TT unknown to the health system of <0.2% in adults aged \geq 15 y in each formerly endemic district.⁴

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At the WHO's 4th Global Scientific Meeting on Trachoma held in 2018,¹ three methods for assessing whether this target had been met were agreed: (i) population-based prevalence surveys powered at evaluation unit (EU) level (the normal administrative unit for healthcare management, consisting of a population unit of 100 000–250 000 people);⁵ (ii) house-to-house case searches; or (iii) a combination of data from multiple adjacent EUs.

Population-based prevalence surveys are the recommended standard approach for estimating the prevalence of trachoma if they are adeauately powered for the disease of interest.⁶ Baseline surveys determine preintervention prevalence, impact surveys estimate prevalence after the last planned round of antibiotic mass drug administration (MDA) is completed and surveillance surveys are conducted at least 2 y after an impact survey has shown the active trachoma elimination threshold has been met, to demonstrate if this has been maintained in the absence of ongoing MDA.⁷ These surveys generally employ a two-stage cluster sampling technique where a small proportion of EU residents are randomly or quasi-randomly selected for examination for signs of trachoma. However, it is important to note that the standard baseline, impact and surveillance surveys are powered for estimating the prevalence of active trachoma as opposed to TT.

Tropical Data is a service that supports health ministries, worldwide, to conduct globally standardised trachoma prevalence surveys, conforming to WHO recommendations^{6,8} and building on the methods and technologies developed as part of the Global Trachoma Mapping Project.⁹ In these surveys, individuals identified as having TT are asked whether they have been offered management (surgery or epilation) by a health worker for the TT (known to the health system) and are referred to a health facility if they have not. In general, baseline, impact and surveillance population-based surveys are not powered to provide sufficient precision around the TT prevalence estimate,⁹ whereas TTonly surveys are specifically aimed to generate more precise data on TT prevalence.⁸ Population-based surveys estimate the prevalence of TT unknown to the health system in individuals aged ≥15 y at EU level to inform programmatic decision-making. If the 0.2% elimination threshold is met, the remaining TT cases should be managed within routine eye care services, whereas if the threshold is not met, public health-level TT surgery services are needed.^{10,11}

House-to-house case searches are aimed at ensuring that all TT cases in a community are found and provided with management through outreach services. Case finding is often conducted by community volunteers who, after a half-day to one-day theoretical and practical training, are tasked to go house-to-house within their community to examine all household members for signs of TT. All households in the community must be covered by case finders. Individuals who are suspected of having TT are then brought to a preorganised outreach site to be examined by a TT surgeon. Those who are confirmed to have TT are counselled and offered management options (i.e. surgery or epilation).¹² Every individual with TT who has received counselling by an eye care professional (typically the TT surgeon involved in trachoma campaigns) is then considered to be known to the health system.¹⁰ Full geographic coverage (FGC) is said to have been achieved when all households in an EU have been visited, all inhabitants,

typically aged >15 y, have been seen by a case finder, and therefore, all TT cases should have been identified and provided with management. Achieving FGC enables the government and partners to be confident that TT has been eliminated as a public health problem, generating data that can be presented in the elimination dossier for validation by the WHO. This approach also ensures that the most vulnerable and marginalised have the option to access services.¹³

However, despite reports of high geographical coverage from implementing partners in various countries, these activities have not always led to the desired <0.2% TT prevalence outcome in population-based prevalence surveys. In several settings, impact, surveillance or TT-only surveys conducted after TT campaigns have shown TT prevalence estimates above the WHO threshold for elimination.¹⁴⁻¹⁶ This study, therefore, sought to explore some of the reasons behind the continuing high prevalence of TT unknown to the health system from population-based surveys in selected EUs in four trachoma-endemic countries, where it was reported that case finding and outreach activities had covered the entire EU. We aimed to determine the magnitude and direction of disagreement in TT prevalence known and unknown to the health system between a standard trachoma impact survey (TIS) and a more detailed questioning and records review process.

To meet the study objective, our study sought to answer the following research questions:

- 1. What proportion of TT cases are accurately allocated at TIS into the category of [a] 'true TT' (i.e. both the TIS team and the study team confirmed the presence of TT) and, among these cases: [b] TT unknown to the health system, and [c] TT known to the health system?
- 2. What are the primary reasons 'true TT cases' are inaccurately allocated to [a] TT unknown to the health system, [b] TT known to the health system, [c] no TT?
- 3. What are the reasons why TT cases truly unknown to the health system fail to have been identified and managed by the programme prior to undertaking postintervention surveys?
 - a. What changes are needed to our approach to case finding and outreach to ensure FGC?
 - b. What changes are needed to our approach to recording and reporting geographic coverage?

Materials and Methods

Design

The study was conducted in eight EUs across four countries: Kenya (Samburu and Igembe North), Ethiopia (Chiro and Gumbi Bordode), Nigeria (Kafin Hausa and Kaugama) and Tanzania (Kiteto and Bahi). These EUs were purposefully selected based on having a historically high TT prevalence estimate,¹⁷ reported having achieved high (full) geographical coverage through case finding and being due for a TIS. The EUs were selected in consultation with the national neglected tropical disease programme, Sightsavers and the Fred Hollows Foundation.

ata co	llection flow chart
	Routine trachoma impact survey (TIS) conducted
	Obtain a list of TT cases from TIS team and their details including community and household
	Review case finder registers and outreach records to identify the cases
	Visit households to examine and interview TT cases
	At the household, identify participant and seek consent to examine
	Examine the participant and ask TT management questions (as per Tropical Data protocol)
	Interview participant using a semi-structured questionnaire
_	Compare the examination and interview findings with the TIS results and information from the case finder and outreach register to determine if the case is a match or mismatch
_	If the case is a mismatch, ask additional questions depending on type of mismatch
	Interview case finder and TT surgeon, where available, to corroborate the findings

Figure 1. Summary of the data collection procedure.

First, a routine TIS was conducted using the Tropical Data protocol by a different team.^{6,18} While it would have been ideal to have our study team join the TIS team in the field for concurrent data collection, the rarity of TT would have meant that the study team remained idle for long periods of time. Therefore, the study team waited from 3 d to 2 wk after the TIS before starting field work. This allowed the study team to obtain a full list of TT cases identified in the TIS to help in planning. Although efforts were made to minimise the time between the TIS and study to ensure that there were no interventions in between, interventions were conducted in Ethiopia the week after the TIS, but before the study team visit. In this case, the study findings were compared with the status at the time of TIS (not the status at the time of the study).

Training

In each of the four countries, the study team consisted of a trachoma grader, a recorder and a community health worker. The team was different from the team involved in undertaking the TIS. Before the field work, all graders and recorders were trained on the study methodology and data collection tools in a 2-d workshop. Because the graders and recorders used in this study were selected from a pool of graders and recorders trained by Tropical Data,¹⁸ no further training on how to grade trachoma or capture the data was conducted. However, the graders and recorders were trained on how to record the number of lashes or location on the data collection forms provided. Teams were also trained on coronavirus disease 2019 (COVID-19) mitigation protocols that were implemented throughout the data collection exercise.

Data collection

For this study, a mixed-methods explanatory approach was employed, utilising several data collection methods (clinical exam-

ination, semi-structured interview and records review). The following data collection procedure, summarised in Figure 1, was followed:

- Step 1: A list of TT cases (name, age, gender and residence) identified during the TIS was obtained.
- Step 2: The outreach records and case finder registers for the communities in which TT cases were recorded in were reviewed to: (1) confirm if the community where each of these cases had been drawn from had been covered by case finding and/or outreach activities; and, if so (2) find out more information about case finding, outreach locations and dates, and management status from the records for each of the cases; and (3) assess whether the identified cases were in the outreach records (i.e. were known to the health system).
- Step 3: The teams then proceeded with the data collection, whereby each team visited the identified cases' households.
- Step 4: At the household, the study team introduced themselves, identified the TT case by name, age and gender based on the information provided by the TIS team, and sought consent to examine and interview the participant.
- Step 5: Once consent was given, the grader examined the participant, each eye separately, using binocular magnifying loupes (×2.5) and adequate lighting, for the presence of TT. Regardless of the presence of TT or not, the grader everted the lid and assessed the presence of a surgical scar. If there was TT, the grader counted the number of lashes and their location (medial, central, temporal, all). The grader then assessed the presence or absence of trachomatous conjunctival scarring. Finally, the grader went through each of the questions regarding TT management, exactly as stated in the Tropical Data

protocol.¹⁸ All data were captured manually on a paperbased data collection form by the recorder.

- Step 6: The participant was then interviewed using a semistructured questionnaire (Supplementary Information) to collect more information, which would be used to determine if the case was known or unknown to the health system The interviews lasted about 10 to 15 min and were audio-recorded. In some instances, the use of a translator was necessary.
- Step 7: The team then compared their findings with the TIS results and information from the case finder and outreach registers, and manually recorded on a paper-based data collection form whether the case was a 'match' or a 'mismatch'. (A 'mismatch' is defined as a discrepancy between the results of case-finding campaigns regarding FGC and the survey findings, or between TIS findings and results of the more detailed assessment conducted in this study.) If the case was a mismatch, additional questions were asked to establish reasons for the mismatch. For example, why were TT cases inaccurately allocated to known, or unknown, to the health system. The interview ended with the grader offering appropriate management to the participant and/or advising them accordingly.
- Step 8: If the village was covered by case finding and the case finder was available, they were interviewed separately to determine whether their responses corroborated the patients' responses and to identify issues with case finding (Supplementary Information 2).
- Step 9: For cases that had had surgery (or were from villages where outreach activities had taken place), the TT surgeons covering that area were also interviewed separately (Supplementary Information 3).

Sample size

All TT cases identified during the TIS, regardless of status (i.e. known, or unknown to the health system), were enrolled in the study.

Data management

All data were entered into standard Excel (Microsoft, Redmond, Washington, United States) worksheets by the recorders and checked for completeness by the study coordinators. The anonymised cleaned data were transferred to the study investigators for analysis. All the records were stored in passwordprotected folders with limited access to study staff, while the paper copies were kept in a secure cabinet.

Data analysis

Quantitative analysis was performed using Microsoft Excel, with a primary focus on descriptive statistics. For information-rich cases, audio-recorded interviews were transcribed verbatim, and the reasons for mismatch were analysed thematically through manual coding of the data. Other notable questions of interest, such

as reasons why patients refused surgery, were also analysed, and grouped accordingly. Variations between EUs (number of mismatch cases and reasons identified) were explored and documented. Additional qualitative analysis was performed to explore factors associated with the misallocation of TT cases or to explain contrasting data from interviews vs case finder registers and outreach records.

Results

Data collection in the four countries was carried out from 16 December 2020 to 10 February 2022. The timing for this study was dependent on the timing of the TIS in the different countries and compounded by COVID-19-associated delays.

Participant overview

Overall, 169 cases were received from the TIS teams. Out of these, 130 cases (77%) were reached and examined in this study. Of the 130 cases examined, 22% were male (Table 1). The age range for the cases was 15–95 y.

The remaining 39 cases were not examined for various reasons, including being absent at the time of the field team visit (82%; n=32), refusal (10%; n=4) and cases whose households could not be reached due to difficult terrain (8%; n=3). Of the missed cases, 92% were female.

TT cases allocation into the 'true TT', known and unknown to the health system categories

Of the 130 cases examined in this study, 90 (69%) cases were a match, that is, both the TIS team and the study team agreed on the TT status of the cases (Table 2). In the known to the health system category, 48% of TIS cases were categorised the same by the study team, while in the unknown to the health system category, 83% of TIS cases were categorised the same by the study team.

The remaining 40 of the 130 cases (31%) were a mismatch. The proportion of mismatch cases varied by country from 13% in Nigeria (n=31) to 43% in Kenya (n=28) (Figure 2). Of the 40 mismatch cases, 12 (30%) were cases that the TIS team had identified as TT cases but the study team did not, 22 (55%) were classified by the TIS team as known to the health system, but the study team found these to be unknown to the health system, and six (15%) were classified by the TIS team as unknown to the health system but the study team found these to be known to the health system (Table 2 and Figure 2).

Reasons why TT cases were inaccurately allocated to unknown to the health system

The study team found that 14 cases that were allocated to the unknown to the health system category by the TIS team were either known to the health system (43%; n=6) or were not true TT cases according to the study team (57%; n=8). The six TT cases that were known to the health system included:

Table 1. Summary of trachomatous trichiasis (TT) cases reached by the study team by country

	Kenya	Tanzania	Nigeria	Ethiopia	Total
Total cases from impact survey	29	68	39	33	169
Total cases reached by study team	28 (97%)	43 (63%)	31 (79%)	28 (85%)	130 (77%)
Gender breakdown of reached cases	4 M; 24 F	8 M; 35 F	10 M; 21 F	6 M; 22 F	28 M; 102 F
Age range of reached cases (y)	30-80	21-95	33–95	15-85	15-95

Abbreviations: F, female; M, male.

 Table 2. Summary of trachoma impact survey (TIS) and mismatch study results

	Known to the health system in TIS	Unknown to the health system in TIS
Known to the health system in mismatch study	24 (48%)—Match	6 (7.5%)—Mismatch
Unknown to the health system in mismatch study	22 (44%)—Mismatch	66 (82.5%)—Match
Non-TT cases in the mismatch study	4 (8%)—Mismatch	8 (10%)—Mismatch
Total	50	80

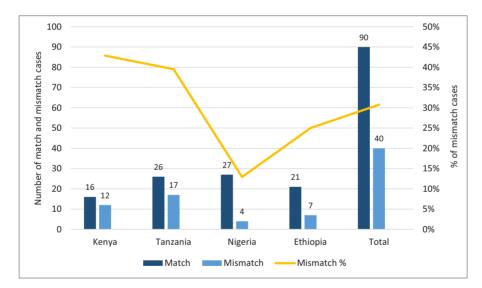


Figure 2. Number and proportion of matched and mismatched trachomatous trichiasis cases by country.

- Three that had postoperative TT in one or both eyes. During the interview, all three denied having had surgery despite having evidence of surgical scars. When probed further, one said that they had had their eyes cleaned.
- One that had surgery scheduled.
- One that had refused surgery.
- One that had attended a surgical outreach camp but was not offered surgery.

Reasons why TT cases were inaccurately allocated to known to the health system

After detailed assessment and interviews with the TT cases, the study team found that 26 cases which were classified as known to the health system during the impact survey were in fact unknown to the health system. Four of these cases were not true TT cases according to the study team (i.e. the study grader did not find evidence of TT).

Table 3. Trachomatous trichiasis (TT) prevalence at the most recent trachoma impact survey (TIS) and case finding coverage in eight evaluation units (EUs) across four countries in Africa; 95% CIs are shown in parentheses

Country	EU	Year of most recent TIS	TT prevalence	TT prevalence unknown to the health system*	Case finding geographical coverage (as reported by implementing partners)	Demonstrated case finding coverage (from records reviewed in this study)
Kenya	Samburu	2020	0.72%	0.26% (0.12-0.45)	91%	29%
	Igembe N	2020	0.52%	0.28% (0.16-0.42)	91%	
Tanzania	Kiteto S	2021	0.94% (0.56-1.46)	0.82% (0.43-1.32)	Close to 100%	47%
	Bahi	2021	0.96% (0.48-1.48)	0.56% (0.30-0.88)	Close to 100%	
Nigeria	Kafin Hausa	2021	0.89%	0.77% (0.31-1.40)	60%	68%
5	Kaugama	2021	0.58%	0.47% (0.17-0.74)	60%	
Ethiopia	Chiro	2022	0.52% (0.26-0.86)	0.23% (0.09-0.43)	100%	93%
ŀ.	Gumbi Bordode	2022	0.14% (0.05–0.27)	0.11% (0.03–0.20)	100%	

*Unknown to the health system is defined as cases that have not been offered any management. Known cases are people with TT in their eyes that have already had surgery for TT, for which surgery has been refused, or for which a surgical date has been agreed. (An aide-memoire for this is: recurrences, refusals and those already referred.)¹⁰

The remaining 22 cases were 'unmanaged' cases, which had been classified as known to the health system by the TIS team. Twelve of the 22 survey participants were not reached by case finders, while the remaining 10 survey participants were reached by case finders but did not attend outreach activities and were not offered counselling by an eye care professional.

Based on responses from the interviews, some of the reasons why cases were inaccurately allocated to the known and unknown to the health system categories can be classified into three broad categories: programmatic factors (micro-planning, case finding and outreach activities), patient-related factors (demographic and sociocultural factors) and grader-related factors (training, time, visibility).

Programmatic factors. Twenty-two of the 40 mismatch cases identified in this study were unknown to the health system (al-though the TIS team classified them as known to the health system). One of the main explanatory programmatic factors is the poor coverage of case finding and outreach activities. In Kenya, Tanzania and Nigeria, the demonstrated coverage of case-finding activities, based on case finder records accessed and reviewed by the study team, was <70% (Table 3), indicating that the EUs had not achieved FGC.

Another programmatic factor is poor documentation or lack of documentation. In Kenya, there were two cases identified in Igembe North, where the outreach records showed that the cases had had surgery, but examination by our independent examiner found no surgical scar. On interviewing the cases, one said that she attended the outreach camp but was not offered surgery, while the other said that she did not attend the outreach camp because she was unwell. When the TT surgeon was interviewed, he indicated that he could not recall these cases.

Finally, for six cases (four in Tanzania and two in Ethiopia), case finders told individuals during home visits that they were not sus-

pected to have TT, and they were therefore not referred to the outreach camp. However, these individuals were later identified (by both the TIS team and the study team) to have TT.

Patient-related factors. For one of the mismatch cases identified in Samburu, Kenya, the patient was found to have a surgical scar, but they denied having had surgery or having been offered surgery. When probed further, the patient said that they had their eyes 'cleaned' but did not have surgery. When interviewed, the case finder who had identified the case 2 y ago indicated that she had advised the patient to go to the surgical outreach camp, but the patient declined due to fear and a previous bad experience following a cataract surgery performed in the right eye.

Other patient-related reasons included the patients not being home during case finding, or the cases being identified at the community level as suspected TT cases but not attending the outreach camp due to fear, competing priorities or other reasons such as sickness. Some of the patients interviewed in this study indicated that:

I was examined last year and this year. I even went to an outreach camp where so many people had gathered to have surgery. As the surgeries began, I ran away due to fear when I saw blood on the eyes of people who had the surgery (patient KH20, Nigeria).

I went to the outreach at health post and the health worker told me I have TT and counselled me for surgery. Since I was alone, I didn't get the surgery because I have no one to support me on my work (patient CH09, Ethiopia).

Another patient-related factor is population movement. According to one of the implementing partners interviewed in this study: Most of the communities are pastoralist communities; they mostly move during the dry season and beginning of the rainy season. Therefore, case finding activities should be planned to coincide with their movements (implementing partner, Nigeria).

Grader-related factors. Twelve of the 40 mismatch cases identified in this study were due to a difference in the clinical findings between the study team grader and the TIS grader. For these 12 cases, the TIS reported them as TT cases, but the study team found them not to be a TT case. Some of the conditions that the study team identified in these 12 cases include suspected glaucoma, chalazion, allergic conjunctivitis, cornea opacity from an injury, non-trachomatous conjunctival scarring and misdirected lashes not touching the eyeball.

Reasons why TT cases that are 'truly' unknown to the health system failed to be identified and managed by the programme

Both the TIS team and the study team found 66 cases to be unknown to the health system and that had not been identified or managed by the programme (Table 2). The study team further classified an additional 22 cases as part of the unknown to the health system category, thereby bringing the total number of cases unknown to the health system to 88 out of the 130 (68%) cases examined.

Discussion

In this study, there was confirmation for 70% of TT cases identified in the TIS, that is, there was a match between the TIS results and the findings of the study team on the TT status of the cases (there is TT, and how the cases were categorised as known or unknown to the health system). Most of those categorised as unknown to the health system were confirmed as such by the study team, but only one-half of those categorised as known to the health system were confirmed as known to the health system. Following interviews and detailed assessment, the main reasons were programmatic, patient-related and grader-related. These results have implications regarding improving TT diagnosis, standardising categorisation of cases as known or unknown to the health system and development of strategies to improve FGC.

A key reason why 'true TT cases' were inaccurately allocated to TT known or unknown to the health system was a difference in the definition of known to the health system. According to the WHO, cases known to the health system comprise people with TT in their eyes that (i) have already had surgery for TT (i.e. they have postoperative TT); (ii) for which surgery has been refused; or (iii) for which a surgical date has been agreed.^{10,19} However, surveys define known to the health system as cases that have been offered TT management (surgery or epilation) by a health worker,¹⁸ with the definition of a health worker being countryspecific and potentially unclear to survey participants, while during house-to-house case finding every individual with TT who has received counselling by an eye care professional (typically the TT surgeon involved in trachoma campaigns) is considered to be known to the health system. To address these discrepancies, there is a need for a clear, standardised definition of a health worker and how to categorise what is known to the health system.

In this study, 56% of the 'true TT cases' were categorised as unknown to the health system by both the TIS and study teams. The main reason for this categorisation was inadequate coverage of case finding and outreach activities. As TT cases become rarer, finding people with TT has become increasingly difficult as the remaining cases are mostly found in remote and underserved areas. As a result, most trachoma programmes have used case finding and outreach strategies to ensure that all suspected TT cases have been found in each community in the targeted area. Unfortunately, house-to-house case searches have not always yielded the desired results, mainly due to low coverage of case finding and outreach activities. Because this study was conducted, stronger case finding guidance has been developed and rolled out to address this issue.

In our study, despite reports of full or near-full geographical coverage (>90%) in six of the eight EUs, 42% of the cases examined were from villages that had not been covered by case finding. This indicates gaps in TT micro-planning and execution of the case finding and outreach approach rather than a failure of the approach itself. Although there were set criteria for selection of case finders, some programmes did not follow these criteria, thereby affecting the output of case-finding activities. In addition, lack of close supervision has been cited as a barrier to delivering case-finding work to the communities.²⁰ Other programmerelated factors that might have affected the case finding and outreach activities include low incentives for the case finders, inadequate training on how to properly identify suspected TT cases, inaccessibility of some areas due to bad terrain, poor weather and insecurity. It is also possible that some of the cases identified during the impact survey and our study had been examined during case finding and found not to have TT (false negatives). This indicates a need for programmes to improve case finder training to ensure that case finders can correctly identify cases during case findina.

Patients' refusal to be examined and/or to attend outreach was another reason for which TT cases remained unknown to the health system. Other studies have shown that a large portion of people suspected as having TT identified during case finding are lost along the continuum of care,²¹ for reasons such as fear of surgery, lack of transport or an escort to outreach, other competing activities, especially during the farming season, lack of consent from their husband (for women to be examined or attend outreach), not convinced they have TT, traditional beliefs about TT, misconceptions regarding recovery time and inability to find a postsurgical caregiver.²¹⁻²³ Because most of the reasons for refusal are modifiable within the structure of a surgical outreach programme, there is a need to revise the outreach strategy to ensure that those patients who are unable to travel to distant outreach locations are not left behind. It is also important that surgical sites are not restricted to health centres to ensure that far-to-reach communities are also not left behind.

Finally, this study found that some cases identified as TT in the TIS were not confirmed by the study team. Although both the TIS and study teams used the WHO simplified grading system for the grading of trachoma²⁴ and were trained trachoma graders, there were several instances where the clinical examination results from the survey and the study varied. Some of the reasons why grader results vary include, for example, the level of training and grader experience.²⁵ For a phenotype like TT, it is also possible that aberrant lashes touching the eyeball could be found at one time but not on another, especially for minor TT.²⁶ To address this, enhanced TT grader training should take place, containing the full spectrum of disease, including counting the number of eyelashes and making use of 3D glasses to improve specificity.^{18,27} To reduce inter-grader variation, there is a need to improve the training and supervision of field-based survey teams to monitor and enhance the quality of data collected in the surveys, perhaps supported with image capture for remote grading.²⁸ To address the grader-related factor of recording non-TT ocular conditions as TT, an option for noting these findings in trachoma surveys could be added to the data collection form.

This study has several limitations. First, because the EUs surveyed were purposively selected to align with the TIS timings, it is likely that they were not fully representative of all EUs in the four countries included in this study. This, coupled with the small sample size, made it difficult to determine statistical significance between the case finding as reported vs the demonstrated case finding coverage, thereby affecting the generalisability of study findings in the broader context. Second, although efforts were made to minimise the time between the TIS and our study to ensure that there were no interventions in between, interventions were performed in Ethiopia the week after the TIS before our study. In this case, the study findings were compared with the status of the TT cases at the time of TIS (not the status at the time of the study). Nonetheless, it is possible that this might have affected the patients' responses or introduced recall bias. Third, some of the patient interviews were conducted in the presence of case finders who found the cases initially. This might have introduced some level of bias in the patients' responses. Fourth, in some districts where records were unavailable to confirm whether case finding had been conducted or whether the case had been found during case finding and offered any type of management, the study team had to rely on the patient's response, which might have introduced some level of bias due to selective memory and/or recall bias. Fifth, our study did not analyse photographic evidence for cases that were found not to be 'true TT cases'. It is therefore possible that the study examiners were wrong about the TT status of some cases. Lastly, it is important to note that our study only reached 77% of the cases identified by the TIS team, which may have introduced bias into the study findings.

Our study shows that there is a need for national programmes to improve coverage of case finding and outreach activities, and review the strategies used for micro-planning, implementation, monitoring and documenting case finding and outreach activities to achieve FGC. Since this study, stronger guidance has been developed and implemented.²⁹ However, a review of the impact of enhanced efforts resulting from this guidance is warranted. Our study also highlights the need to improve TT case diagnosis during surveys and case finding exercises to ensure validity and reliability, principally through enhanced training and supervision. Further, standardisation across approaches in terms of classification of cases as known to the health system is required to enable comparability of results.

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Data availability: The data that support the findings of this study are available from the corresponding author on request.

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