



# Piloting a trachomatous trichiasis patient case-searching approach in two localities of Sudan

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**Background:** Approximately 1.9 million people have become blind or visually impaired from trachoma, the leading cause of infectious blindness. Trachoma prevalence surveys conducted in Sudan have shown that thousands of Sudanese suffer from the advanced stages of the disease, trachomatous trichiasis (TT), and warrant sight-saving surgery. Sudan's National Trachoma Control Program (NTCP) provides free TT surgery; however, given that many TT patients live in remote areas with limited access to health services, identifying patients and providing eye care services has proved challenging. For this reason, the Sudan NTCP piloted a systematic TT case-finding approach to identify patients.

**Methods:** In Gedarif state, 11 villages in Baladyat el Gedarif locality and 21 villages in West Galabat locality were included in a TT case-searching activity from September to November 2018. TT case finders were selected from the villages where the activity took place and were trained by ophthalmic medical assistants to identify possible patients.

**Results:** Of 66 626 villagers examined, 491 were identified as having TT by TT case finders. Of those, 369 were confirmed as true cases by the TT surgeons, a 75.2% (369/491) success rate.

**Conclusions:** The TT case-finding approach provides an example of an effective method for identifying TT patients and should be expanded to other parts of the country known to be endemic for trachoma.

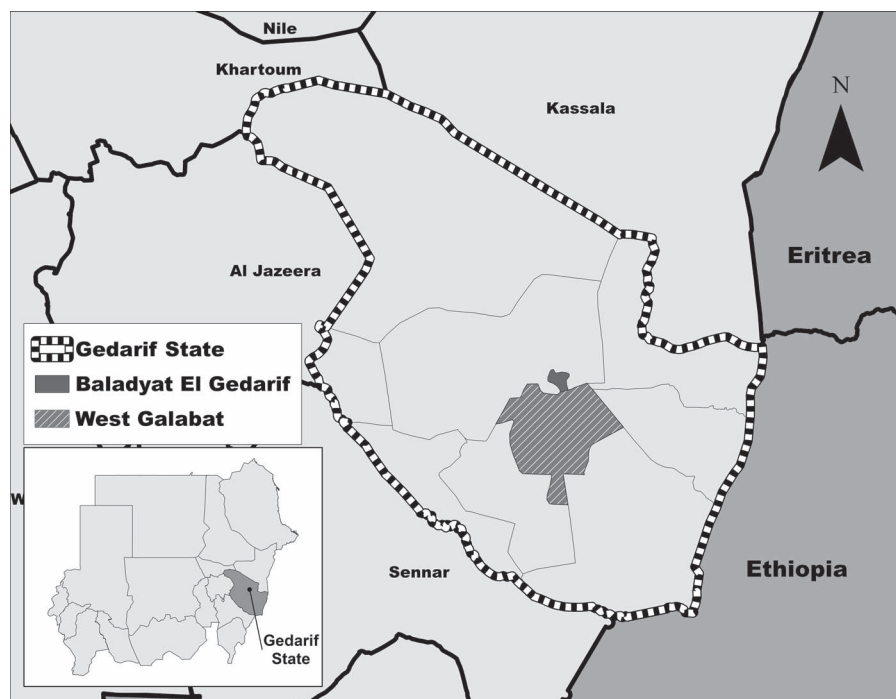
**Keywords:** case search, Sudan, surgery, trachoma, trachomatous trichiasis

## Introduction

Approximately 1.9 million people have become blind or visually impaired from trachoma, the leading cause of infectious blindness.<sup>1</sup> The World Health Organization (WHO) adopted the SAFE strategy to eliminate trachoma as a public health problem:<sup>2</sup> **S**urgery to correct in-turned eyelashes, **A**ntibiotic distribution to treat infection and **F**acial cleanliness and **E**nvironmental improvement to prevent the disease. In many countries, the advanced stage of the disease that requires surgery, trachomatous trichiasis (TT), is beyond the capacity of countries to address as part of routine eye care services. A person is considered to have TT when one or more eyelashes from the upper lid are touching the globe, often as a result of the eyelid turning inwards after years of repeated scarring.<sup>3</sup> Failure to correct the in-turned eyelashes results in corneal abrasions leading to a cascade of physical damage, secondary infections, corneal opacity and irre-

versible blindness. Ultimately the goal is to reduce the prevalence of TT to <0.1% of the total population or, as commonly abbreviated, <0.2% in those  $\geq 15$  y of age.<sup>4</sup> Once TT is decreased below this threshold it is assumed that TT is no longer a public health problem and incident cases of TT can be managed by routine eye care services.

Trachoma affects the poor and marginalized, who often lack the ability to access routine healthcare services either due to distance from healthcare sites or because of financial reasons. Additionally, the life cycle of trachoma results in women being disproportionately affected.<sup>5</sup> To prevent citizens from going blind and to ensure that all those who need TT surgical services have access to them, national trachoma elimination programs such as the Sudan National Trachoma Control Program (NTCP) typically provide free surgical services in trachoma endemic districts. These surgical outreach camps often extend outside of the typical healthcare setting and are organized close to the villages



**Figure 1.** Map of Baladyat el Gedarif and West Galabat localities.

where patients live. Despite the provision of free sight-saving services, the prevalence of TT remains  $>0.2\%$  in adults  $\geq 15$  y of age in many parts of Sudan and the identification of TT patients and surgical uptake remains low. Based on documented success in Kenya,<sup>6</sup> Nigeria<sup>7</sup> and Tanzania<sup>8</sup> of using TT case finders to ensure all patients who need TT surgery were being identified and offered surgery, the Sudan program piloted a TT case-finding approach in two localities in Sudan: Baladyat El Gedarif and West Galabat (Figure 1). Information from the pilot program allowed the NCTP to identify patients, provide surgery and evaluate how case-finding practices could be improved moving forward.

## Methods

### Setting

Political administrative structures are organized by state, locality (the local name for a district), administrative unit and village. In order to determine if the WHO trachoma elimination as a public health problem targets of  $<5\%$  trachomatous inflammation – follicular (TF) in children 1–9 y of age and TT  $<0.2\%$  in those  $\geq 15$  y of age have been met, the NCTP conducts cross-sectional population-based prevalence surveys at the locality level. In Sudan, these prevalence surveys examine children 1–9 y of age for five clinical signs of trachoma and adults  $\geq 15$  y of age for TT. Prevalence estimates from these surveys are used for program planning. Baseline prevalence mapping showed that of 131 localities surveyed, 78 localities were  $>0.2\%$  TT in those  $\geq 15$  y of age, with one locality having a TT prevalence as high as 6.7%.<sup>9,10</sup> These prevalence levels translated to  $>42\,000$  people suspected to need TT surgery to prevent blindness.<sup>11</sup> Based on

previously reported surgical output of approximately 2000 TT surgeries per year, this means it could take almost 20 y before this surgical backlog is cleared.

In order to clear the surgical backlog and provide services to those who need it, surgical camps are organized at the locality or administrative unit level and often held at healthcare units. Typically patients are identified within the village, transported to the surgical site on the day of surgery if they are unable to transport themselves and then returned to their household on the same day. Programmatic impact surveys conducted between 2016 and 2017 in seven localities showed that despite these outreach efforts, the prevalence of TT in adults  $\geq 15$  y of age still exceeded the 0.2% threshold in six localities.<sup>12</sup> The program therefore embarked on an intensive TT case-finding program between September and November 2018 in the trachoma endemic localities of Baladyat el Gedarif and West Galabat, Gedarif state, Sudan in order to ensure as many TT patients as possible were identified by the health system and offered services.

### Ethics statement

Oral informed consent was obtained from all adults  $\geq 15$  y of age before they were examined for TT. Ethical clearance to examine adults for TT was obtained from the Sudan Federal Ministry of Health and was considered part of routine health service provision.

### Training

A locality coordinator was identified for each locality, who in turn selected one team leader per village. Team leaders were responsible for selecting the case finders in their villages accord-

**Table 1.** Baladyat el Gedarif and West Galabat locality population and case-finder data

Characteristics	Baladyat el Gedarif	West Galabat
Population	310 907	595 150
Villages in the locality, n	109	88
Villages included in the case-finding pilot, n	11	21
Population living in villages in case-finding catchment area	82 183	72 82
Case finders trained, n		
Female	71	24
Male	5	71
Case finder leaders, n		
Female	3	3
Male	7	18

ing to specific criteria. These criteria included being trusted by the community, prior experience volunteering with a health program, ability to read and write in Arabic, ability to understand the local language and willing and able to counsel community members on health matters. Both males and females were included in the case-finding program (Table 1).

A one day classroom training session was conducted for all case finders. The trainers were experienced national public health officers from the Sudan NTCP, NTCP ophthalmic medical assistants (OMAs) and a Carter Center Trachoma Program officer. The International Coalition for Trachoma Control (ICTC) Training Curriculum for Trichiasis Case Finders manual was used as the basis for the training.<sup>13</sup> Topics covered in the training included, but were not limited to, basic information about trachoma, the SAFE strategy, how to identify trichiasis, how to conduct house-to-house TT case searches and how to provide counselling to trichiasis cases and their family members about the importance of obtaining surgery. They were also trained on how to complete the TT patient registration documentation. During the one day training, trainees practiced examination techniques and counselling on each other. TT patients and non-TT patients were included in the training to provide a hands-on practical training component for the trainees. The TT patients had varying degrees of TT, ranging from one eyelash to multiple lashes touching the eye. Under the supervision of the OMAs, the trainees examined the TT and non-TT individuals and provided counselling. All TT cases involved in the training were offered surgery after the training was complete.

### Case search strategy

Each case finder was given a reference sheet with pictures of TT, Arabic information pamphlets on trachoma that could be left with suspected TT cases and TT patient registration forms. They were expected to spend four days moving from house to house within their village. Supervision was conducted by the public health officers and the OMAs. In Baladyat el Gedarif locality, the

**Table 2.** Reasons 194 identified TT cases did not have surgery, by locality

Reason	West Galabat	Baladyat el Gedarif
Epilated	0 (0)	11 (5.7)
Overtly declined	54 (27.8)	61 (31.4)
Did not present for surgery <sup>a</sup>	19 (9.8)	38 (19.6)
Referred to hospital	4 (2.1)	7 (3.6)

Values are presented as n (%).

<sup>a</sup>Patients accepted an appointment for surgery but did not present at the appointment time.

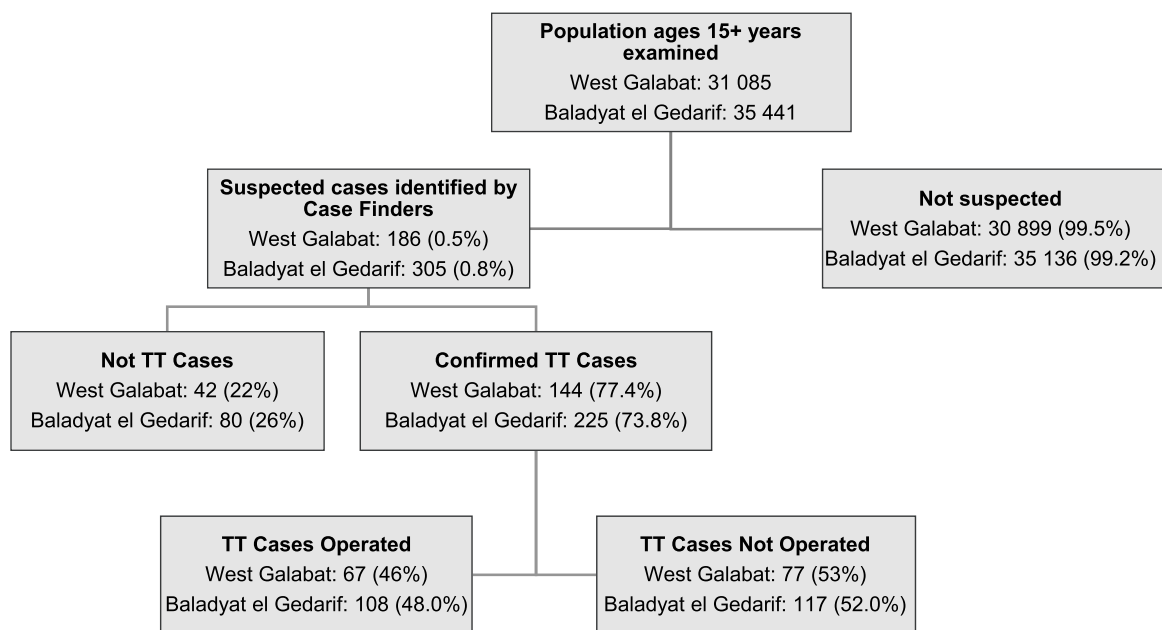
state capital of Gedarif state, 'villages' had a higher population as compared with other counties (Table 1), therefore 11 villages were included as part of the catchment area. One OMA was responsible for five villages while another OMA was responsible for six villages. Case finders moved house to house and examined residents  $\geq 15$  y of age for TT. They documented suspected cases on TT registration forms and notified team leaders of any suspected TT cases through text messaging or in person. After compiling a list of all suspected patients in the team leader's catchment area for that day, the team leader would then notify the OMA of the suspected cases identified. Within  $<24$  h the OMA would visit each suspected case at the household level and confirm whether the person had TT and document it on the TT registration form. In West Galabat locality, this same approach was used; however, 21 villages were searched. Three OMAs were each assigned seven villages and were responsible for confirming reported TT cases. At the completion of the case-finding activity, a list of confirmed TT cases was created for both localities. The list of confirmed TT cases in each village was provided to each team leader along with information on the date and place of the next scheduled TT surgery camp.

## Results

Across the two localities, 32 villages used the case-finding method of identifying TT cases, with 66 526 residents examined for TT (Figure 2). Of those examined, case finders suspected that 491 had TT. OMAs confirmed that of those suspected, 369 (75.2%) had TT and needed intervention. Of the 369 identified as needing TT surgery, 175 (47.4%) received the surgery. There were 194 identified TT cases who did not receive surgery, either because of being epilated (6%), referred to a hospital (6%), overtly declining (59%) or not presenting themselves for surgery on the scheduled day (29%) (Table 2). Of the 369 TT cases confirmed, 24 (6.5%) were recurrent TT cases who had received TT surgery at least one time previously.

## Discussion

Case finders had a 75.2% (369/491) success rate in correctly identifying a person who had TT, thereby showing that utilizing



**Figure 2.** Flow chart of TT case-finding examinations and outcomes.

village members with proper training can be an effective method of identifying TT cases within their village. A total of 369 patients were identified with TT and around half (186/369) had their TT managed either through TT surgery or epilation. This output shows that even after identification and counselling, people with TT are still unable or unwilling to undergo surgery. For the 115 patients who overtly declined surgery and the 57 patients who stated their willingness to get surgery but did not present on the assigned date, the teams did not document the reasons these TT cases decided not to undergo surgery. Suspected reasons included patients traveling outside the village on the day of surgery, feeling unwell, fear of surgery, lack of childcare while the mother is away from the house for the operation or other responsibilities such as working on a farm, since the case-search activity was conducted during the peak agricultural season.

Overall, the NTCP considered the TT case-finding program a success. By narrowing down the number of people suspected of having TT, the amount of time TT surgeons spent examining patients was reduced, thereby reducing the number of days surgeons needed to be in the field. This reduction in days decreased costs to the trachoma program and increased the likelihood that TT surgeons, often ophthalmologists from Khartoum, would participate in the program, as their time away from their private practice was less. Identifying patients before the surgical camp was organized allowed program managers to better estimate the time needed for the camp and the supplies needed. Using respected members of the community increased the villagers' willingness to be examined for TT and accept counselling about the importance of undergoing surgery. The exercise found that using volunteers and health workers based in the village was more helpful than using medical personnel from the locality or state clinics, as often these medical staff were busy and lacked sufficient time to visit all households and villages. Lastly, by recruiting at least two case finders per village from the village

they were expected to cover, the amount of time spent searching for patients was not overly burdensome for any single volunteer.

The case-finding pilot identified lessons to be applied to future case-finding activities and overall trachoma program activities. Gedarif state is an important agricultural region of Sudan. Typically the rainy season runs from June through November. This can make reaching remote villages with vehicles difficult, which in turn can impact the ability to move patients from the village to the surgical site. The harvesting period also occurs during this period, with many village residents working on either their personal farms or on commercial farms. Given that the pilot took place during this peak season, identifying patients at home or patients willing to undergo surgery could have been impacted as this economic competing priority could have negatively influenced a patient's willingness to undergo surgery at the time it was being offered. Future surgical campaigns should therefore be offered outside of this seasonal period in order to provide the identified patients with follow-up opportunities for surgery. Given that surgery uptake was close to 50%, the national program should also consider conducting a survey to understand patients' perceived barriers to TT surgery and other reasons for refusing surgery.<sup>14,15</sup> The case-finding activity only documented suspected TT cases that were confirmed as having TT. It is therefore unknown if there were any false negatives. When possible, future case searches should attempt to determine what proportion of the reported TT-negative people were truly negative and what proportion actually presented with TT and were therefore 'missed'. Given the 75% success rate of the trained case finders at confirming TT, the history of surgical campaigns in these two localities and the low levels of TF, we expect these false negatives to be low<sup>12</sup>; however, confirming the proportion of false negatives could be useful in determining the effectiveness of the case-finding training program and its implementation. Lastly, as national programs begin to use case-searching approaches

to document that the WHO TT elimination threshold has been met, it will be important for national programs to document the proportion of adults included in the case-searching activities in future work. This will allow national programs to document that endemic populations have been reached and that there are no TT patients unknown to the health system.

## Conclusions

Recognizing that provision of TT surgical services is a critical activity for the Sudan NTCP in order to clear the backlog and achieve the elimination of trachoma as a public health problem, the Sudan program piloted a TT case-finding approach to help fine tune the best way to reach these TT patients. This pilot showed that utilizing village members with proper training can be an effective method of identifying TT cases within their village. It also found that just identifying patients and offering surgery is not enough. Refusals were still high and therefore more effort is needed to understand why patients are refusing surgery and to ensure patients receive this sight-saving surgery. The Sudan program should scale up this TT case-finding approach in all localities with TT >0.2% in those  $\geq 15$  y of age. This will ensure that those suffering from TT are reached by medical services. Additionally, it will enable the Sudan NTCP to be confident that all villages have been reached and there are no TT cases unknown to the health system.

**Authors' contributions:** AMS, MA, NA, EKC and BEE participated in study design and protocol development. MA, NA and BEE participated in study implementation. AMS, MA and BEE analysed and interpreted the data. AMS and MA wrote the first draft. All authors participated in critically revising the manuscript and approved the final version. AMS and BEE are guarantors of the paper.

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**Competing interests:** None declared.

**Ethical approval:** Oral informed consent was obtained from all adults  $\geq 15$  y of age before they were examined for TT. Ethical clearance to examine adults for TT was obtained from the Sudan Federal Ministry of Health and considered part of routine health service provision.

## References

- 1 World Health Organization. Trachoma fact sheet. <https://www.who.int/news-room/fact-sheets/detail/trachoma> [accessed 28 February 2019].
- 2 World Health Organization. *Report of the 3rd Global Scientific Meeting on Trachoma*. Baltimore, USA, 19–20 July, 2010. Geneva: World Health Organization, 2010.
- 3 Taylor HR, Burton MJ, Haddad D et al. Trachoma. *Lancet* 2014; 384(9960):2142–52.
- 4 World Health Organization. Validation of elimination of trachoma as a public health problem. June 2016. [https://www.who.int/neglected\\_diseases/resources/who\\_htm\\_ntd\\_2016.8/en/](https://www.who.int/neglected_diseases/resources/who_htm_ntd_2016.8/en/) [accessed 12 December 2018].
- 5 Cromwell EA, Courtright P, King JD et al. The excess burden of trachomatous trichiasis in women: a systematic review and meta-analysis. *Trans R Soc Trop Med Hyg* 2009;103(10): 985–92.
- 6 Karimurio J, Rono H, Njomo D et al. Use of validated community-based trachoma trichiasis (TT) case finders to measure the total backlog and detect when elimination threshold is achieved: a TT methodology paper. *Pan Afr Med J* 2017;27:84.
- 7 Ramyil A, Mpyet C, Courtright P, Dami N. Use of an inexpensive magnifier with light source in the diagnosis of trichiasis among community-based case finders in Nigeria. *Ophthalmol* 2018;25(Suppl 1):138–42.
- 8 Greene GS, West SK, Mkocho H, Munoz B, Merbs SL. Assessment of a novel approach to identify trichiasis cases using community treatment assistants in Tanzania. *PLoS Negl Trop Dis*. 2015; 9(12):e0004270. pmid:26658938.
- 9 Hassan A, Ngondi JM, King JD et al. The prevalence of blinding trachoma in northern states of Sudan. *PLoS Negl Trop Dis*. 2011;5(5):e1027.
- 10 Elshafie BE, Osman KH, Macleod C et al. The epidemiology of trachoma in Darfur States and Khartoum State, Sudan: results of 32 population-based prevalence surveys. *Ophthalmol*. 2016; 23(6):381–91.
- 11 Carter Center. SAFE in Sudan. In: *Proceedings of the Nineteenth Annual Trachoma Program Review: Celebrating 20 Years of Impact*. Atlanta, GA: Carter Center; 2018. [https://www.cartercenter.org/resources/pdfs/news/health\\_publications/trachoma/trachomareview-final-eng-2018.pdf](https://www.cartercenter.org/resources/pdfs/news/health_publications/trachoma/trachomareview-final-eng-2018.pdf) [accessed 29 May 2019].
- 12 Sanders AM, Abdallah Z, Elshafie BE et al. Progress toward elimination of trachoma as a public health problem in seven localities in the Republic of Sudan: results from population-based surveys. *Am J Trop Med Hyg* 2019;101(6):1296–1302.
- 13 International Coalition for Trachoma Control. Training curriculum for trichiasis case identifiers. February 2016. <http://www.trachoma-coalition.org/sites/default/files/content/resources/files/SmallICTC%20TrichiasisCaseFindersTrainingCurriculum%20-compressed.pdf> [accessed 23 July 2019].
- 14 Bickley RJ, Mkocho H, Munoz B, West S. Identifying patient perceived barriers to trichiasis surgery in Kongwa district. *Tanzania. PLoS Negl Trop Dis* 2017;11(1):e0005211.
- 15 Rajak SN, Habtamu E, Weiss HA et al. Why do people not attend for treatment for trachomatous trichiasis in Ethiopia? A study of barriers to surgery. *PLoS Negl Trop Dis*. 2012;6(8):e1766.