

## Reviews and Opinions

# Social Sciences for the Prevention of Blindness

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**Abstract:** Organizations working for the elimination of *Chlamydia*-triggered blindness (trachoma) follow the WHO SAFE strategy (surgery for trichiasis, antibiotics, face washing and environmental changes) with the aim to achieve a minimum of 80% of children with clean faces in endemic communities, mass treatment covering the whole district with trachoma rates of 10% or more and surveillance plans.

Trachoma recurrence that is common after implementing the SAFE strategy 3, 5 or even 7 times evidence that the cognitive processes requiring assimilation and integration of knowledge did not register with parents, caretakers and children. Moreover, repeated awareness campaigns to improve hygiene did not systematically produce irreversible changes of behavior in neglected populations. In view of this evidence, the rational behind mass drug administration as the mainstay of preventable blindness elimination demands a wider scope than simple mathematical models. The reluctance to see disappointing outcomes that leads to repeated interventions may suggest from a sociologic point of view that the strategies are products of those evaluating the activities of those who fund them and vice versa. A similar articulation emerges for reciprocal interactions between researchers and those judging the pertinence and quality of their work. So far, the lack of autocratic elimination strategy approaches may expose inbred circles that did not properly grasp the fact that antibiotics, trichiasis surgery and education limited to improvement of hygiene are inefficient if not associated with long-term basic educational actions in schools.

**Key words:** Chlamydia, trachoma elimination, antibiotics, hygiene, SAFE, sociology, inbred, scholasticism, education, schooling

## EFFECTIVENESS OF FUNDING IN ORGANIZATIONS WORKING TO ELIMINATE PREVENTABLE BLINDNESS

Trachoma is one of the oldest bacterial diseases known to humans and yet today remains the world's leading cause of preventable blindness. Globally, 1.2 billion people live in endemic regions, many in poor rural areas with limited access to sanitation and basic education [1]. The World Health Organization (WHO) estimates that more than six million people are blinded by trachoma [1, 2].

The conjunctival inflammation triggered by the intracellular bacteria *Chlamydia* leads to trachoma, especially in people living in conditions of extreme poverty [2]. The early signs of active trachoma are diagnosed by everting the upper eyelid, while the presence of *Chlamydia* in conjunctival cells is assessed using nucleic-acid amplification techniques (PCR) [2–4]. Repeated or chronic infections with *Chlamydia* may result in scarring of the eyelid, and the in-turned lashes rubbing the globe (trichiasis) may pro-

voke corneal scarring and blindness.

For the elimination of trachoma, the World Health Organization (WHO) established the SAFE strategy based on the implementation of four components: surgery for trichiasis (S), administration of active antibiotics to kill *Chlamydia* (A), face washing (F) and environmental changes (E) [1–3, 5]. Surgical correction of trichiasis is an integral part of the WHO effort to eliminate blindness from trachoma by the year 2020. However, the recurrence rates following surgery for trichiasis have been reported to be disappointingly high [6].

## UNDERSTANDING STRUCTURE, FUNCTION AND EFFECTIVENESS OF ACTIONS FOR THE PREVENTION OF EVITABLE BLINDNESS FROM BACTERIAL ORIGIN

Presently, the governmental and non-governmental organizations working for the elimination of trachoma concentrate their efforts on following the SAFE strategy. Their aim is to achieve a) a minimum of 80% of children (1–9

years old) with clean faces in the endemic communities; b) mass treatment of the entire district with follicular trachoma rates of 10% or more (WHO recommends repeated interventions with at least three repeated rounds of antibiotics and impact surveys regardless of whether or not vil-

lages had initial low prevalence rates) [5, 7, 8], and c) the development and implementation of surveillance plans in countries that have reached their ultimate intervention goals [9–11].

Several private corporations in the U.S.A. have a

Table 1.

Organization	Activities	Website/Reference
The World Health Organization (WHO)	associates the Alliance for the Global Elimination of Blinding Trachoma by the Year 2020 (GET2020) with the Trachoma Scientific Informal Workshop (TSIW) for the implementation of the SAFE strategy.	[2, 13]
The United Nations (UN) Secretary-General's campaign to end open defecation by 2025	provides opportunities for synergy with trachoma control activities according to the SAFE strategy	[14]
The UN General Assembly	advocates the right to safe drinking water and sanitation (UN General Assembly resolution A/RES/64/292).	[15]
WHO/United Nations Children's Fund (UNICEF) Joint Monitoring Programme for Water Supply and Sanitation	advocates access to drinking water and sanitation	[16]
WHO/UNICEF Integrated Global Action Plan for the Prevention and Control of Pneumonia and Diarrhoea	provides a framework for ministries of health to coordinate goals and targets.	[17]
U.S. Agency for International Development (USAID)	participates in scaling up mass drug administration programmes according to the SAFE strategy.	[18]
International Coalition for Trachoma Control (ICTC)	supports the 2020 Alliance and advocates the SAFE strategy in the implementation of control programs.	[19]
Global Trachoma Mapping Consortium (GTMP)	develops WHO protocols for the implementation of the SAFE strategy.	[20]
The Queen Elizabeth Diamond Jubilee Trust	participates in the implementation of the components of the SAFE strategy.	[21]
Sightsavers with support from the British government	is associated with partners on trachoma control according to WHO guidelines.	[22]
Sight First (Lions Clubs International Foundation)	operates against trachoma following the SAFE elimination strategy	[23]
The Carter Center's Trachoma Control Program	supports trichiasis surgery, participates in the construction of household latrines and assists in health education and mass drug administration of antibiotics.	[24]
Christian Blind Mission (CBM)	supports the WHO guidelines according to the SAFE strategy components.	[25]
Helen Keller International	establishes programs based on the SAFE components.	[26]
Orbis International	works in developing countries through eye care training with local organizations.	[27]
Pfizer Inc. and the Edna McConnell Clark Foundation	co-established the not-for-profit organization International Trachoma Initiative (ITI) with governmental and nongovernmental agencies to implement the SAFE strategy.	[26, 28–29]
The Water, Sanitation and Hygiene program at WHO (WASH organization)	provides support for trachoma elimination programs with particular emphasis on the promotion of behavioral change and the need for a sound evidence base of action.	[30]

Table 2.

NTD NGDO partners	Activities	Website/Reference
World Vision International	improves children's health	[32]
Organisation pour la Prévention de la Cécité	assists populations in French-speaking developing countries	[33]
The International Agency for the Prevention of Blindness	leads international efforts in blindness prevention activities, particularly in rural areas.	[34]
Light for the World	confederates national development NGOs committed to saving eyesight and improving the quality of life.	[35]
Eyes of the World	especially helps children who suffer from poor vision.	[36]
The Fred Hollows Foundation	restores sight and trains eye doctors in developing countries.	[37]
The Eye Mission of the Lions Clubs International Foundation	supports projects to prevent blindness, restore eyesight and improve eye health and eye care.	[38]
World Vision International for Children	works to overcome poverty.	[39]
RTI International (funded by the U.S. Agency for International Development)	provides assistance to NTDs control through the NTD NGDO Program and the ENVISION Project (2011–2016).	[40]

strong tradition as funding organizations for the promotion of medical care. These organizations support patient advocacy groups, professional medical associations and charitable organizations in the 501(c) tax status environment (donations contribute to lower tax bills). The legitimate tax deduction must be addressed to a qualified organization, and to be tax-exempt under section 501(c) of the Internal Revenue Code, none of the organization earnings may inure any private individual, nor may the organization influence legislation as part of its activities or participate in any activity for or against political candidates. The organizations described in section 501(c) must not be organized or operated for private interests and are commonly referred to as “charitable organizations” [12].

The funding of not-for-profit organization programs eligible for healthcare contributions target health screening, advocacy of disease awareness, patient access to medical care and patient education for hygiene. The vast majority of the institutions committed to the fight against preventable blindness are outlined below (Table 1).

In 2013, the Alliance for the Global Elimination of Blinding Trachoma by the Year 2020 recognized the need for a) surveys at the sub-district as well as district level; b) improved laboratory tests for *Chlamydia*; c) post-endemic surveillance in urban areas with unoperated trichiasis; d) improvement and standardization of surgical procedures to minimize trichiasis recurrence and e) cost assessment for achieving high massive drug administration [2, 13]. Presently, more than 225 million doses donated by Pfizer have been distributed since the start of the drug donation program in 1998. Moreover, the neglected Tropical

Disease Nongovernmental Development Organizations Network (NTD NGDO) [31] and its public-private partnerships facilitates among other actions, the distribution of antibiotics (Table 2).

#### LIMITATIONS OF MEDICAL INTERVENTIONS FOR THE ELIMINATION OF TRACHOMA

As largely reported, the antibiotic (azithromycin) administered to treat trachoma is bioavailable and highly active against the intracellular microorganisms triggering trachoma (*Chlamydiae*) [41, 42]. This antibiotic eradicates *Chlamydia* from the conjunctival cells in a few weeks and dramatically reduces the clinical signs of active trachoma (follicles in the conjunctiva) [8, 9, 43]. Moreover, azithromycin treatments revealed no evidence that *Chlamydiae* lost their susceptibility to this antibiotic by post-transcriptional methylation of the 23S bacterial ribosomal-RNA, either plasmid or chromosome-mediated [44, 45]. In addition, people treated for trachoma have never shown *Chlamydia trachomatis* susceptibility-reduction associated either with enzymes (esterase or kinase) that inactivate azithromycin or with the synthesis of efflux proteins that drain this antibiotic outside of the bacteria [45, 46].

Globally, the heterogeneity of clinical trials makes it inappropriate to analyze data on the four components of the SAFE strategy. In fact, 14 trials that included 3,587 participants and 15 trials that included 8,678 did not allow highlighting of the real impact of antibiotic treatment on the long-term elimination of clinical active trachoma, showing first, that clinical signs of trachoma re-emerged in

treated communities, and second, that *Chlamydia* genomes were detected in conjunctival samples after repeated implementation of the four components of the SAFE strategy. The evidence at this point suggests that trachoma was partially reduced but not eliminated by repeatedly implementing the WHO strategy [43, 47–49]. These facts suggest that the microbiological episteme makes it unreasonable to justify the repeated administration of active antibiotics in the same district to the same people (5, 7, 9 times or even more) to treat susceptible germs, and therefore that further analysis cannot be restricted to mathematical predictors, laboratory results or the opinions of eye-surface specialists [11, 43, 49, 50]. At this point, special attention should be paid to efforts made in Morocco, Oman, Nepal and Gambia for the elimination of preventable blindness from bacterial origin. In these countries, surprisingly, the dramatic decrease in trachoma was the result of strong government commitments to basic education supported by health-care institutions, with or without implementing the SAFE strategy [51–54].

#### F AND E: FACE WASHING AND ENVIRONMENTAL IMPROVEMENT AND THE ROLE OF SOCIAL SCIENCES IN THE ELIMINATION OF PREVENTABLE DISEASES

In trachoma elimination strategy, dirty faces in children have been cited as the main pathway by which *Chlamydia* spreads in people with ocular and nasal discharge [2, 55, 56]. The components F and E of the SAFE strategy are founded on the idea that instruction on hygiene during the promotion of sanitation is the fundamental behavioral key to trachoma elimination. Accordingly, the dissemination of information about cleanliness (F and E components) was expected to produce massive behavioral changes and a comprehensive understanding of the factors encouraging the transmission of germs [57, 58]. Nevertheless, trachoma recurrence is frequent in districts in which all the SAFE components were implemented, and the limited success of the F and E components (after awareness campaigns) sounds a warning about the inefficient transmission of knowledge and the lack of integration of risk factors into people's daily activities. The frequency of dirty faces persisting after the SAFE strategy shows that the cognitive processes requiring assimilation and integration of knowledge did not register with parents, care takers and children [55, 59, 60]: only one out of three studies (SAFE strategy) shows significant results for the reduction of trachoma prevalence after conveying information on the need for improved hygiene [11, 47, 61, 62].

#### SOCIAL RESEARCH TO SUPPLEMENT MEDICAL APPROACHES

It was reasonable to expect the elimination of antibiotic-susceptible bacteria triggering the chronic inflammatory conjunctival processes that lead to blindness after implementation of all four components of the SAFE strategy (once or repeatedly). In reality, however, trachoma was neither irreversibly eliminated nor prevented, and recurrences required a repetition of pharmacologic interventions seven or even more times [10, 11, 43, 48, 63].

Social sciences may help to identify factors that shape organizational error regarding concepts understood not as purely academic but for their ethical relevance [64, 65]. Several organizations with high ethical ideals assisted in efforts to help not-for-profit institutions working for the elimination of preventable blindness in neglected populations [1, 2, 13–40]. Their support makes it possible to fund implementation of the four components of the SAFE strategy, including the payment of salaries, transportation, drugs, housing and costs for planning and executing mass drug distribution. In this context, social research tools that clarify the relationships, rules and processes among individuals within institutions suggest that the reciprocal actions clustered into enclaves of the like-minded with those sharing the same views may crystallize in a multi-organizational state (donor, university, non-governmental organizations, etc.) where anything outside the limited opinion of nominators, nominees and genitors becomes troublesome (scholasticism) [66, 67]. Bringing qualified experts together has led to the assumption that good decisions will result from the groupthink that may emerge in cohesive groups working under conditions of directive leadership to support the views advocated by leaders [67]. These social products display a strong confirmation bias in that they focus on information that confirms initial opinions, and, with a sense of invulnerability, groupthink rebukes different opinions and points of view [67, 68]. In addition, the human structures producing and perpetuating concepts that reproduce answers from a set of axioms (possibly resulting in refractive behavior while facing evidence) are labelled by social sciences as scholastic [68]. Accordingly, the repeated antibiotic treatments to kill antibiotic-susceptible bacteria could be seen as the product of scholastic structures confining the good intentions of donors within internal information networks, from which members obtain knowledge reinforcement and legitimization that promotes the *status-quo*. Finally, it is pertinent here to include social-psychology approaches that describe human beings as frequently averse to acting contrary to the trend of a group due to fear that the group will express

negative attitudes towards them or even exclude them [69, 70]. Out of deference to authority and a desire to maintain a harmonious working environment and order to achieve unity of purpose and act as a single entity, members may suppress their concerns and meaningful criticism about dogmas and practices [66].

### EXPLORING ATTITUDE

Consequently, hegemonic ways of thinking may have been legitimated and transformed into governmental actions without substantial questioning. Concepts and actions were built in a context in which the people implicated in decisions about workers' future and careers may have been affected by those they named or funded. In the same intricate arena, it is surprising that members from certain organizations often evaluate the activities of those that fund them and vice versa, with a similar functional structure for reciprocal interactions between researchers and those judging the appropriateness, pertinence and quality of their work [71–73]. Under these circumstances, disruptive issues are ignored or become homogenized into acceptable terms by previous concepts [74]. Sociology research warns of the danger of abstaining from proper actions if the same elements simultaneously or successively play the role of judge, party, fundraiser, nominee, nominator, employee, employer, fund distributor, employee, manager, researcher, researcher evaluator, publisher and editor [75–77].

So far, the reluctance to see disappointing outcomes (after repeated pharmacologic and awareness interventions) hampers further discussion and encourages silence for the sake of harmonious working environment and consensual tendencies in inbred organizations [67, 74, 75]. In sociology, the term “inbred” is a metaphor connoting an act of incest, the difference being that it is conducted to preserve “desirable” achievements [78, 79].

### ELIMINATION OF PREVENTABLE BLINDNESS FROM BACTERIAL ORIGIN: THE URGENT NEED FOR BASIC EDUCATION

It should be emphasized that public and private institutions fighting against diseases must be supported unconditionally if they operate with open-mindedness and receptiveness to diversity (the remedy to recalcitrant decisions, dogma, groupthink and silence). Therefore, the present analysis does not recommend simple opposition to expert organizations; rather the aim is to understand fundamental assumptions and to prevent institutional productions from being taken for granted. In view of the evidence that the SAFE components may have produced equivalent

health improvements through basic schooling (reading, writing, logic analysis and calculation skills) [51–54], it is time to underline (beyond the scope of ophthalmologists, microbiologists and epidemiologists) the need to assess the limits of the components of the current elimination strategies because the global picture shows that:

- a) repeated awareness campaigns to improve hygiene according to the SAFE strategy may not produce irreversible behavior changes;
- b) hygienic improvements cannot be conclusively transmitted only by medical approaches;
- c) short-term visits to the affected populations during the implementation of the SAFE strategy are insufficient to ensure the integration of knowledge;
- d) microbiological approaches are disconnected with the reality of illiterate people;
- e) social sciences offer vital tools for the assessment, diagnosis, knowledge and reconstruction of the dysfunctional practices (scholasticism, dogma, silence, groupthink, inbred) [65–68, 80];
- f) antibiotics may eliminate trachoma when associated with basic educational actions [81].

In conclusion, the limited success of medical interventions in eliminating transmissible diseases in neglected populations raises an urgent need for interagency engagements advocating basic education programs [43].

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