INFORMAL CONSULTATION ON A TRACKING SYSTEM FOR PATIENTS WITH TRACHOMATOUS TRICHIASIS

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ROLLINS SCHOOL OF PUBLIC HEALTH, EMORY UNIVERSITY, ATLANTA, USA

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Meeting report

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Abbreviations

TT	Trachomatous trichiasis
WHO	World Health Organization

1. Background

1.1 There is international commitment to eliminate trachoma as a public health problem by 2020 [1]. This requires, in all formerly endemic districts, both a low prevalence of active trachoma, and a prevalence of trachomatous trichiasis (TT) unknown to the health system[1] of <1 case per 1000 total population [2].

1.2. The global trachoma elimination programme is fortunate to have multiple funded initiatives that have recently begun contributing technical and financial resources to addressing the TT backlog in trachoma endemic countries.

1.3. On behalf of patients being offered management of TT, we have a responsibility to monitor the work supported by the funded initiatives, and to monitor routine TT management in all trachoma-endemic countries. This responsibility is shared by individual surgeons, their supervisors, ministries of health, supporting partners, donors and WHO. There is a need to monitor indicators that reflect (a) output (e.g., the number of surgeries performed), (b) equity (e.g., the sex of patients receiving surgery, and the geographical coverage of surgical services), and (c) quality of surgery. Doing so involves collection of data on each operation performed for TT and (on at least a subset of those operations[2]) collection of outcome data for patients. Appropriately aggregated data are then generated for each stakeholder.

1.4 Monitoring systems for TT surgery have until now mostly been developed under the auspices of individual national trachoma elimination programmes.

1.5 In response to particular donor requirements, the regulatory environments of the countries in which they work, and the standard operating procedures of individual grant managers, the funded initiatives referred to in paragraph 1.2 have designed their own systems for data collection and monitoring. Each of the funded initiatives has a different system. Now that these initiatives are being scaled up, they are beginning in some places to overlap geographically, with the result that some national programmes (and even some surgeons) are having to use more than one system. This causes tension, increases the work of surgeons and national programme managers, and increases the likelihood of data errors. In addition, system development work is being duplicated at international level, and none of the systems currently being developed seems to fully address all of the programmatic issues that are potentially solvable by a good, standardized system.

1.6 There is therefore an urgent need to create a common system for registering patients with primary (previously un-managed) TT and tracking them through the patient pathway, that could be made available to everyone, meet the data needs that exist at all levels of all programmes, require minimal training, and be offered and supported at no cost to programmes.

1.7 To take advantage of the fact that a number of stakeholders would be in Atlanta from 1-2 October 2015, the World Health Organization (WHO) asked Emory University (as an institution seeking designation as a WHO collaborating centre for trachoma) to put together a meeting on 30 September 2015, to permit discussion and generation of consensus on the components of such a system, and to plan its development.

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[1] Known cases of TT include recurrent cases and cases who have refused surgery, which must be recorded as part of the surgical information system. Cases who are listed for surgery but not yet operated are also classified as "known" if the delay is for logistic reasons but a surgical date is set [2].

[2] Discussion of the minimum number, or proportion, of each surgeon's cases that should be followed up for appropriate outcome monitoring was outside the scope of this meeting.

The **agenda** and **list of participants** for the meeting comprise Annex A and Annex B, respectively, of this report.

1.8 The consultation was informed by the following:

(a) The WHO manual, “Trichiasis surgery for trachoma (2nd edition)” [3]

(b) The “Surgery Day Trichiasis Patient Record” within the International Coalition for Trachoma Control manual, “Organizing trichiasis surgical outreach” [4]

(c) Consultations within the funded initiatives about patient tracking needs

(d) Briefings about systems in use, in development, or under consideration (Table 1).

1.9 Other previous, ongoing and planned work relating to TT management includes investigation of the most effective and efficient case finding strategies; consideration of whether an operation designed to correct entropion is appropriate for eyes in which there is trichiasis without entropion [5]; the place of recommending epilation instead of a surgical procedure [6-8]; the use of absorbable instead of non-absorbable suture material [9]; mannequin-based training for TT surgery [10]; the optimal position of the incision in relation to the eyelid margin [11]; the optimal management of post-operative TT; and the optimal management of lower lid trichiasis; amongst other things. The scope of this meeting was deliberately restricted to the data needs for routine management of primary trachomatous trichiasis. In particular, the consultation aimed to determine **what core data are needed by which trachomatous trichiasis stakeholders, at what time points?** The consultation then aimed to define **how the trachoma community could unite to ensure that those data are collected and appropriately processed and presented, in ways that safeguard the respective interests of patients, surgeons, programmes, partners, funders and the Alliance for Global Elimination of Trachoma by 2020.**