About ESHealth34 – A Clinical Information Collection Tool.

ESHealth34 is a Clinical Information Collection Tool. It was developed with the input from many different organisations and individuals. As such it is an example of a positive collaborative venture that emerged as together we continue to fight Ebola and support survivors.

During the second half of the 2014-2016 Ebola Epidemic it became apparent that long term medical care was needed by many survivors of Ebola Virus Disease. Some Ebola treatment units that had capacity continued to care for their own survivors after discharge. Survivors also attended a variety of other health care outlets. Each has developed their own system of documentation. In March 2015 as part of the overall co-ordination of the epidemic, organisations caring for survivors were asked at an UNMEER meeting to send examples of such documentation to a database study lead by ISARIC and coordinated by Laura Merson. They collected documents from all over the epidemic, including documentation developed at Military Hospital 34 and the Ebola Treatment Unit in Port Loko. ISARIC produced a database format with a core of minimum information and supplementary modules in collaboration with the Wellcome Unit in Ho Chi Minh City, Vietnam. This was placed on the ClinRes platform. Field trials in Military Hospital 34 in Freetown, and in the ETU in Port Loko identified some areas where changes were needed. However by the time field evaluations were completed, it was no longer possible to make alterations to the database with the coding team in Vietnam who were by this time reassigned to other projects.

Continuing in collaboration with ISARIC further development was undertaken on paper and we aspired to a new platform - a simple database structure that could be developed, managed and altered in Sierra Leone, used on paper or computer and if needed developed for other platforms such as smart phone or tablet. This clinical data collection tool was based on the previous work with ISARIC and put together by pan-organisation team, coordinated from Military Hospital 34 (Col Dr. Foday Sahr and team) with academic support from ISARIC clinical academics at the University of Liverpool (Dr Janet Scott and Dr. Calum Semple). This activity was funded by the Wellcome Trust's Enhancing Research Activity in Epidemic Situations programme (ERAES).

Input forms and feedback on the forms developed from them was gathered from the following sources:

Focus groups consisting of clinical staff caring for survivors at Military Hospital 34 in Freetown – particularly on general history and examination requirements. Partners in Health in Port Loko, (particularly for ophthalmology with input and advice from Dr Matthew Vandy, Consultant Ophthalmologist, Connaught Hospital Freetown). The clinical teams in Connaught Hospital, particularly and the Sierra Leone Kings Partnership (particularly on neurology and psychosocial aspects).

Credit is therefore due to the following large group of people – and there may be those whose names have become detached from the work that they did in the iterative process for collection of forms. Apologies to them.
Clinical Teams:
Military Hospital 34, Freetown, Sierra Leone: Col. Prof. Foday Sahr, Lt. Dr. Foday Sesay, Ct Dr. Thomas Massaqui, Maj. Dr. Stephen Sevalie and their clinical team.
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ISARIC (University of Oxford), Oxford, UK Dr. Laura Merson
Wellcome Trust Clinical Research Unit, Ho Chi Mihn City, Vietnam: Nguyen Thanh Tien, Huynh Van Nhat Lac, Ho Van Hien

Instructions.
When the patient first attends – fill out initial assessment and any initial modules indicated by the patients problems. At the patient’s subsequent visits (follow ups) – fill out the follow up assessment (this includes the patients QLD problems and how the patient has improved or not) plus any modules indicated by the patients problems the last time (follow up modules – again these include more detail about how the patient has improved or not). PLUS any modules indicated by the patient NEW problems (Initial Modules).

Acknowledgements
These forms are free to be used for the collection of data or as inspiration for other projects. We would appreciate the work of this consortium being acknowledged where appropriate in the following form. ‘The ESHealth34 Data Collection Tool’ https://isaric.tghn.org/protocols/ebola-data-tools/

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