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| **Institution:** University of Sussex | | |
| **Unit of Assessment:** 1 – Clinical Medicine | | |
| **Title of case study:** Providing the evidence base for national policies and interventions towards eliminating podoconiosis | | |
| **Period when the underpinning research was undertaken:** 2005 – 2020 (ongoing) | | |
| **Details of staff conducting the underpinning research from the submitting unit:** | | |
| **Name(s):** | **Role(s) (e.g. job title):** | **Period(s) employed by submitting HEI:** |
| Gail Davey | Professor of Global Health Epidemiology | 2007 – present |
| Kebede Deribe | Research Fellow | 2016 – present |
| Melanie Newport | Professor (Honorary Consultant) in Infectious Diseases and International Health | 2004 – present |
| **Period when the claimed impact occurred:** 2014 – 2020 | | |
| **Is this case study continued from a case study submitted in 2014?** N | | |

## 1. Summary of the impact

Research led by Davey, Newport and Deribe at the Centre for Global Health Research (CGHR), Sussex, has provided important evidence – including detailed podoconiosis (podo) mapping – which has informed the Ethiopian and Rwandan Governments' agendas on podo control, prevention and treatment. In partnership with the Ethiopian government and national NGOs, the Sussex team contributed to the implementation of podo care management initiatives in the most endemic areas, which resulted in the treatment of 70,000 podo patients (approximately 5% of the national total) and the training of over 500 health workers to identify and treat podo cases. The CGHR team has also led the first trial of a simple, inexpensive foot care package in reducing podo-related acute inflammatory episodes in Ethiopia. This care package is now included in the WHO Skin Neglected Tropical Diseases (NTDs) training package for health workers, in the Rwanda NTD Master Plan 2019-2024 and in the Ethiopia NTD Master Plan 2020-2025.

## 2. Underpinning research

Podoconiosis (hereafter referred to as podo) is a non-infectious disease arising in barefoot individuals who are in long-term contact with irritant red clay soil of volcanic origin. Major symptoms include swelling of the lower limb (lymphoedema) and acute painful attacks. The disease has major social and economic consequences through stigma and loss of productivity. Globally, there are around four million people with podo, mainly in tropical Africa, Central and South America, and Southeast Asia. As recently as 2010, the condition was not mentioned in the health policy of any of the 32 endemic countries, so no patient was able to receive treatment. Since 2005, staff from the Centre for Global Health Research (CGHR) at Sussex have been conducting wide-ranging research to address some of the most urgent knowledge gaps, particularly around disease distribution, mental health consequences and management. This case study focuses on the research most immediately relevant to national and global elimination of podo. The research described is unique and distinctive; the team has contributed more than 95% of the articles on podo published in the past decade.

CGHR acts as the research hub for a unique global NGO advocacy for podo, Foot*work* (https://podo.org) for which Davey is the Executive Director. All the research referenced in Section 3 was supported by grants awarded to the Sussex team at the CGHR and delivered in partnership with academics and non-academic collaborators based in the UK and overseas (mainly Ethiopia and Rwanda). Amongst the research stakeholders were representatives from the targeted countries' Health Ministries, as well as NGOs active in the delivery of podo prevention and care programmes.

### Understanding the distribution of podo

Reliable and detailed data on the prevalence and distribution of podo globally are scarce. In many endemic countries, podo is confused with Lymphatic Filariasis (LF), another condition

manifested by leg swelling but with a different cause (parasites transmitted by mosquitos). Estimating the number of people with podo according to geographical location is important for programme planners and health care providers, who plan, monitor and evaluate control and elimination efforts. This need was addressed by CGHR research through the production of a comprehensive mapping of podo distribution and prevalence [**R1; G1, G3**]. Between June and September 2013, the team, in collaboration with the Ethiopia Federal Ministry of Health, generated the first nationwide integrated mapping of podo and LF in Ethiopia. By combining nationwide survey data with spatially referenced information on a range of environmental factors, the CGHR team identified human and environmental risk factors for podo and the endemic districts requiring prioritised intervention. In 2017, the research team used a geostatistical modelling approach on the nationwide mapping data [**R1; G1, G3**] to estimate the number of podo cases [**R2; G1, G2**]. The analysis gave an estimate of 1,537,963 podo cases in Ethiopia in 2015, with 99% of the cases being in remote parts of the three largest Regional States. This analysis also provided a framework for modelling the distribution of podo in other endemic countries, such as Rwanda. Nationwide mapping in Rwanda was conducted in 2017 supported by the Wellcome Trust-funded 'Global Atlas of Podoconiosis' [**R3; G2**]. In partnership with the Rwanda Biomedical Center (the research arm of the Rwanda Ministry of Health), Deribe and Davey demonstrated that podo was widespread in Rwanda with 80% of people with swelling of the lower limbs considered to be podo cases.

**What are the mental health consequences of podoconiosis?**

In 2007, Deribe and Davey, in collaboration with Addis Ababa University, conducted a survey of knowledge, attitudes and practices in a community highly endemic for podo [**R4; G4**]. It revealed that most community members, including health professionals (HPs), held negative, stigmatising attitudes towards social interactions with people affected by podo. This finding advocated for HPs' training and the inclusion of educational components in community interventions for podo, aimed at dispelling misconceptions and stigma. In 2014, the team investigated depression prevalence in people suffering from podo, and the link between depression, disability and podo [**R5; G3**]. This study demonstrated for the first time that podo sufferers were more likely to have depression, and that both depression and podo were independently associated with higher disability levels.

**How should podo be treated in low-resource settings?**

From 2014-2017, Davey and Newport led a community-based Randomised Controlled Trial (RCT) in northern Ethiopia, of a simple leg swelling (lymphoedema) treatment package funded by the Joint Global Health Trials Initiative (MRC/WT/DFID). The GoLBeT trial was the first trial to assess the effects of a lymphoedema management package on the most important clinical consequence of podo – lymphoedema acute attack. These attacks have devastating consequences in terms of pain, reduced productivity and potential progression to sepsis. The trial recruited 696 people with podo and showed that the package of foot hygiene, skin care, exercise, elevation, and use of socks and shoes reduced the incidence and duration of acute lymphoedema attacks [**R6; G5, G6**].

## 3. References to the research


**R1**. **Deribe, K.**, Brooker, S. J., Pullan, R. L., Sime, H., Gebretsadik, A., Assefa, A., Kebede, A., Hailu, A., Rebollo, M. P., Shafi, O., Bockarie, M. J., Aseffa, A., Reithinger, R., Cano, J., Enquselassie, F., **Newport, M. J., & Davey, G.** (2015). Epidemiology and Individual, Household and Geographical Risk Factors of Podoconiosis in Ethiopia: Results from the First Nationwide Mapping. *The American Journal of Tropical Medicine and Hygiene*, *92*(1), 148–158. https://doi.org/10.4269/ajtmh.14-0446

**R2**. **Deribe, K.**, Cano, J., Giorgi, E., Pigott, D. M., Golding, N., Pullan, R. L., Noor, A. M., Cromwell, E. A., Osgood-Zimmerman, A., Enquselassie, F., Hailu, A., Murray, C. J. L., **Newport, M. J.**, Brooker, S. J., Hay, S. I., & **Davey, G.** (2017). Estimating the number of cases of podoconiosis in Ethiopia using geostatistical methods. *Wellcome Open Research*, *2*, 78. https://doi.org/10.12688/wellcomeopenres.12483.2

**R3**. **Deribe, K.**, Mbituyumuremyi, A., Cano, J., Bosco, M. J., Giorgi, E., Ruberanziza, E., Bayisenge, U., Leonard, U., Bikorimana, J. P., Rucogoza, A., Turate, I., Rusanganwa, A.,

Pigott, D. M., Pullan, R. L., Noor, A. M., Enquselassie, F., Condo, J. U., Murray, C. J. L., Brooker, S. J., … **Davey, G.** (2019). Geographical distribution and prevalence of podoconiosis in Rwanda: A cross-sectional country-wide survey. *The Lancet Global Health*, *7*(5), e671–e680. https://doi.org/10.1016/S2214-109X(19)30072-5

**R4**. Yakob, B., **Deribe, K., & Davey, G.** (2008). High levels of misconceptions and stigma in a community highly endemic for podoconiosis in southern Ethiopia. *Transactions of The Royal Society of Tropical Medicine and Hygiene*, *102*(5), 439–444. https://doi.org/10.1016/j.trstmh.2008.01.023

**R5**. Bartlett, J., **Deribe, K.**, Tamiru, A., Amberbir, T., Medhin, G., Malik, M., Hanlon, C., & **Davey, G.** (2016). Depression and disability in people with podoconiosis: A comparative cross-sectional study in rural Northern Ethiopia. *International Health*, *8*(2), 124–131. https://doi.org/10.1093/inthealth/ihv037

**R6**. Negussie, H., Molla, M., Ngari, M., Berkley, J. A., Kivaya, E., Njuguna, P., Fegan, G., Tamiru, A., Kelemework, A., Lang, T., **Newport, M. J.**, McKay, A., Enquoselassie, F., & **Davey, G.** (2018). Lymphoedema management to prevent acute dermatolymphangioadenitis in podoconiosis in northern Ethiopia (GoLBeT): A pragmatic randomised controlled trial. *The Lancet Global Health*, *6*(7), e795–e803. https://doi.org/10.1016/S2214-109X(18)30124-4

**Indicators of field-leading research:** Prof Davey is the Executive Director of 'Foot*work*' the International Podoconiosis Initiative (www.podo.org). She is also an Expert Advisor to the Ethiopian National Podoconiosis Action Network (NaPAN). In 2020, Prof Davey was elected President of the Royal Society of Tropical Medicine & Hygiene, and awarded an Officer of the Order of the British Empire award in the Queen's Birthday Honours for services tackling NTDs.

**Grants supporting the research:**

**G1.** Deribe [PI]. (2013-2016): Nationwide mapping of podoconiosis in Ethiopia. [099876]. Wellcome Trust PHATIC International Training Fellowship £272,808 [**R1, R2**]

**G2.** Deribe [PI]. (2016-2021). Global Atlas of Podoconiosis. [201900]. Wellcome Trust Intermediate International Fellowship £660,064 [**R2, R3**]

**G3.** Davey [PI], Newport [Co-I]. (2010-2015). Gene-environment interactions in podoconiosis. [091956]. Wellcome Trust University Award. £550,000 [**R1, R5**]

**G4.** Newport [PI], Davey [Co-I]. (2007-2010). The genetic basis of podoconiosis - a model for gene-environment interaction? [079791] Wellcome Trust. £280,187 [**R4**]

**G5.** Negussie. (2013-2016). Defining and managing acute adenolymphangitis in podoconiosis lymphoedema in Northern Ethiopia. University of Sussex Chancellor's International Research Scholarship. £48,600 [**R6**]

**G6.** Davey [PI], Newport [Co-I]. (2013-2017). Randomised Controlled Trial of Podoconiosis Treatment in Northern Ethiopia. [MR/K007211/1]. MRC/DFID/Wellcome Trust Joint Global Health Trial. £777,890 [**R6**]

## 4. Details of the impact

### 1. National Podoconiosis Prevention, Control and Elimination Policy: Ethiopia & Rwanda

Information from studies conducted by staff at the CGHR has shaped policy in two countries in East Africa – Ethiopia and Rwanda. The route to impact is via Neglected Tropical Disease (NTD) Masterplans, which each endemic country is required to draw up to receive donations for Mass Drug Administration (community-wide preventive therapy). Due to the co-productive nature of the research conducted in each country, CGHR members provided research-based evidence as part of the development and writing of the Masterplans, thus ensuring the rapid implementation of their research findings.

### 1.1 Ethiopia – evidence-based national NTD Masterplan and healthcare programmes

LF/Podo integrated mapping. In Ethiopia, evidence from CGHR research on podo informed the first edition of the country NTD Masterplan 2013-2015 (Deribe K. et al., *Parasit. Vectors*, 2012), and the need for a nationwide mapping of the disease. At subsequent national NTD review meetings, Deribe and Davey presented CGHR findings on podo mapping [**R1**] and estimation of the disease burden [**R2**], which in turn informed the Ethiopia NTD Masterplan second edition 2015/16-2019/20 [**S1**]. As a result, the country met two milestones for podo elimination [**S1**] by

2016: (1) completion of podo mapping and identification of endemic districts [**S2, R1**], and (2) burden assessment in 58 (16%) of the districts [**S2**].

Healthcare programmes – the Preventing Podo Project (PPP). In 2014, Davey and colleagues were successful in securing a UK Big Lottery Fund grant for an implementation project coordinated by the Ethiopian National Podoconiosis Action Network (NaPAN) – an NGO bringing together researchers, policy makers, clinicians, and representatives of all groups offering care to patients with podo in Ethiopia. The PPP was a three-year implementation project (2014-2017, GBP499,078 award + in-kind/financial support, total GBP2,214,745), aiming to extend small-scale interventions of podo case management in the three regions of Ethiopia most affected by podo [**R1**]. The successful project application was based on the CGHR research on the social [**R4**] and mental health impact of podo [**R5**]. The project contributed to the capacity building of 370 government health professionals and 182 health extension workers trained in podo morbidity management [**S2**], with 67% expressing confidence in their ability to provide podo care [**S3**]. As a result, 68,181 podo patients (around 5% of the national total) who would otherwise not have had access to treatment, were treated for podo and 115,653 individuals in podo endemic districts were educated on the disease through 1,150 community events, 55 district workshops, and 16 rounds of national radio campaigns [**S3**]. A network of 18 patient-led groups was also established for a more sustainable and accessible community-based approach to podo [**S3**]. Finally, the PPP was instrumental in catalysing [text removed for publication] [**S2**].

Development of the LF/Podo Morbidity Management and Disability Prevention (MMDP) guidelines. Davey and Deribe contributed to the development of the LF/Podo MMDP guidelines [**S4**] via NaPAN, using CGHR data on the mental health impact of podo [**R5**]. These research findings enabled advocacy for psychological and socioeconomic support to complement medical and surgical care, which ensured full reintegration of patients into their communities [**S4**]. These findings helped to define the patient counselling element of the care package, alongside medical care. As of February 2016, the guidelines were used to train a total of 300 health care workers and full coverage of the MMDP guidelines had been achieved in 87% of endemic districts, leading to the treatment of 153,250 people [**S2**].

Lymphoedema Management Package. The GoLBeT trial provided the research-based evidence for a simple treatment intervention on which to base national policy. It showed that a simple, inexpensive care package was effective in reducing the frequency and duration of acute lymphoedema attacks resulting in increased work productivity and quality of life [**R6**]. In March 2019, the results of the trial were presented at workshops held to draft the third National Masterplan alongside CGHR research on podo burden assessment [**R2**]. The GoLBeT care package is set to be incorporated in the next five-year Ethiopian NTD Masterplan (2020-2025) [**S5**] and has been used by the [text removed for publication] [**S8**].

**1.2 CGHR-led podo research contribution to Rwanda NTD Strategic Plans**

In Rwanda, the CGHR research [**R3**] has been described as “an impressive and substantial undertaking […] reaching more than 1:10 Rwandans” and resulting in 282 community health workers being trained to identify podo cases [**S6**]. The findings contributed to advocacy for podo interventions in the 2017-2020 NTD Strategic Plan [**S7a**] and CGHR staff advised on the podo elimination plan. In 2018, the study results were presented internally within the Rwanda Ministry of Health and underpinned the podo section of the 2019-2024 NTD Strategic Plan, which sets the strategies to reduce the burden of the disease by 2024 [**S7b, S8**]. Amongst these initiatives are the training of health professionals, establishment of 10 podo treatment centres in the most affected districts, and education of the population to the importance of foot hygiene and shoe-wearing. Through Foot*work*, CGHR secured a three-year (2020-2023) implementation award funded by the IZUMI Foundation to support the government in this first step [**S8**]. [text removed for publication]. The CGHR IZUMI award is critical for Rwanda’s government to implement the podo-specific initiatives laid out in its NTD Strategic Plan, due to limited internal resources available to tackle this disease.

**2. Global Advocacy on podo elimination**

CGHR research on podo prevalence and distribution mapping in Ethiopia and Rwanda has been pivotal for disease advocacy. In 2010, Davey was invited to give a presentation to the WHO

Neglected Tropical Diseases department about podo which, until then, was not one of the diseases considered by the department. As a result of this presentation, the WHO NTD department integrated podo under its "other neglected tropical conditions". This recognition by the WHO catalysed significant changes to policy development within Ethiopia. Through this recognition, the country was able to include podo in their 2013-2015 NTD Master Plan and mobilise essential resources (such as the network of district-level NTD-leads) to control the disease [**S9**].

In 2018, the WHO NTD department put together a pictorial training guide on neglected tropical diseases of the skin for district health workers, to support capacity building in the diagnosis and treatment of NTDs. Davey and colleagues' research informed the podo section of the WHO training guide [**S10**] which has since been converted into an interactive new mobile phone app [**S11**]. Dr Jose Postigo, Medical Officer, Skin NTDs team, WHO Department of Control of NTD, at the announcement of the app's launch in July 2020, explained its significance as follows:

> "This software application will quickly allow health care workers and the public to get information about a specific disease – such as its clinical features, management and geographical distribution – and also provide a list of potential diagnosis." [**S11**]

In July 2020, Davey and colleagues, [text removed for publication], put together a series of user-friendly slides on podo for district health workers training on the disease. This includes the latest GoLBeT care package [**S12**].

**5. Sources to corroborate the impact**


**S1.** Ethiopia Federal Ministry of Health (FMOH) NTD Master Plan Second Edition 2015/16-2019/20 (pp21-22, table 7 p27 & table 17 p40).
**S2.** Testimonial statement from [text removed for publication] describing CGHR role in the country's effort to prevent, control and treat podo.
**S3.** UK Big Lottery Fund PPP Final Evaluation Report (October 2017) - Independent evaluation by Nucleus Health and Social Affairs Consultancy, of the PPP implementation project.
**S4.** Ethiopia FMOH LF/Podoconiosis MMDP guidelines February 2016 (p23 & p29)
**S5.** Review of the Joint Global Health Trials funding scheme, Final Report, authored by Technopolis Group. November 2019 highlighting the impact of GoLBeT (pp2-3).
**S6.** Marks, M., & Mitja, O. (2019). *The Lancet Global Health*, *7*(5), e554–e555. https://doi.org/10.1016/S2214-109X(19)30158-5
**S7a.** Rwanda 2017-2020 NTD Strategic Plan (December 2017; p26); **S7b.** Rwanda 2019-2024 NTD Strategic Plan (May 2019; p20 & p54).
**S8.** Testimonial statement from the [text removed for publication] describing Davey et al. role in podo mapping and in Rwanda's programme response.
**S9.** Ethiopia FMOH letter of support submitted as part of the dossier led by Prof Davey advocating for podo integration as a WHO NTD (December 2016).
**S10.** WHO Skin NTD Training Guide for Health Workers, 2018.
**S11.** WHO Skin NTD Webpage – App launch https://www.who.int/news/item/16-07-2020-neglected-tropical-diseases-of-the-skin-who-launches-mobile-application-to-facilitate-diagnosis
**S12.** Email records showing [text removed for publication] request to Prof Davey for [text removed for publication] generated by Prof Davey in July 2020.